Programs for
Frail Elderly Persons,
Persons with Dementia
and their Caregivers

A Review

The DPA Group Inc.

Programs for Frail Elderly Persons, Persons with Dementia and their Caregivers

A Review

Conducted for the
Elderly Services Branch,
Ontario Ministry of Community
and Social Services

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January, 1990

The DPA Group Inc.

90-05441/

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1.0 INTRODUCTION

An estimated 69,550 senior citizens in Ontario, or about 6 per cent of the population aged 65 and over in 1988, have moderate or severe dementia. The number of people with dementia is forecast to increase by 55 per cent between 1988 and 2001, barring any major advances in prevention and treatment. This increase reflects a general increase in the population 65 and older and within that group, increases in the population 75 years and older that is more likely to be afflicted by dementias.

The care of dementia patients raises economic and social issues that affect us as individuals and as families and that challenge our social and political institutions. As Cohen (1986,3) observes:

> The rapid aging of our society guarantees that no individual nor institution will be untouched by the bittersweet success of increased longevity. Those of us who escape the ravages of chronic illness will be caring for those who are afflicted.

The costs of care will be borne by tax-supported health and social services and by individuals who enable a loved one suffering from dementia to live in the community for as long as possible. The burden shouldered by these caregivers is considerable; even as they are gradually losing a spouse, parent or other loved one to the dementing illness, they must cope with the increasing strain of providing 24-hour care and the emotional, physical and economic hardships that entails.

Since 1986, the Ministry of Community and Social Services has been funding community-based programs to help persons with Alzheimer's disease and related dementias, and their caregivers. MCSS now wishes to tap the funded agencies' experience with dementia programs and place it in the broader perspective of experience elsewhere, in order to refine program policies in Ontario. Accordingly, it has contracted The DPA Group Inc. to conduct this Review of Programs for Frail Elderly Persons, Persons with Dementias and Their Caregivers.

1.1 Purpose of the Study

The general purpose of this study is to provide MCSS with descriptive information on:

- the nature of dementia;
- the incidence of dementia in Ontario;

- the needs of caregivers and persons with Alzheimer's disease and related dementias; and
- day programs, respite programs and other programs in Ontario and elsewhere for persons with dementias and their caregivers.

This information has been obtained by the study team through a literature review, discussions with key informants, and a survey of all community-based dementia programs funded by MCSS. Detailed objectives for each of these exercises were developed in the Terms of Reference for the study and explored through subsequent discussions between MCSS officials and the study team.

This document reports on the literature review and discussions with key informants. As requested by MCSS, the approach has been to describe, not to analyse, the literature, although special attention has been given to the findings of studies incorporating a component of evaluation. In this way, the study team has attempted to make the review as useful as possible for MCSS' evaluation of its own approach and of the programs it funds. The number of programs detailed in the literature is relatively small. The survey findings are presented under separate cover.

1.2 Organization of the Report

The subject headings and content of this report follow the detailed objectives set in the Terms of Reference for the literature review and interviews with key informants. Section 2.0 examines the nature of dementia: causes, stages and symptoms of dementia generally and Alzheimer's disease in particular.

Section 3.0 discusses the prevalence of Alzheimer's disease and related dementias in Ontario, a key to health and social services planning. Prevalence rates developed through studies outside Ontario are used to estimate the number of cases in the province. As a basis for comparison, prevalence estimates based on a survey of dementia patients in Ontario institutions are presented. Also included is a summary of current work by the federal government -- the Health and Activity Limitations Survey and a multicentre epidemiologic study -- that promises to clarify prevalence of the disease throughout the country.

Section 4.0 examines the needs of persons with Alzheimer's disease and related dementias, and their caregivers. The focus, limitations and major findings from the literature are presented with a concluding note on their policy implications.

Section 5.0 describes the literature on dementia programs outside Ontario. Examples of respite programs, day programs and caregiver education and support groups are described in terms of services offered, costs, clientele, staff and facilities. The issues and problems facing each type of program are then discussed.

Section 6.0 focuses on studies that have evaluated programs or program components for their efficacy in relieving caregiver stress and in benefitting patients. It also probes the literature for findings on interventions that help patients continue to live in the community and that help patients with no family or surrogate caregiver. Community prerequisites to establishing effective programs, future trends, and guidelines for programs outside Ontario are also discussed.

Supplementing the literature on dementia programs, which is particularly limited for Canada, is Section 7.0. Key informants across the country outside Ontario were contacted and questioned about the availability of programs designed specifically for elderly patients with dementias. The results provide a general picture of services available.

The final section (8.0) deals with dementia and respite programs in Ontario, although the major initiative in the province -- the programs being funded by MCSS -- will be covered in a separate document.

Appendix A describes the procedures used to conduct the literature search. Key informants are listed in Appendix B. Ontario chapters of the Alzheimer Society of Canada are contained in Appendix C.

2.0 THE NATURE OF DEMENTIA

2.1 Definitions of Alzheimer's Disease and Related Dementias

Dementia is a syndrome that embraces a wide range of conditions and is defined as a global deterioration of mental functions, especially cognition, memory, feeling and behaviour. Different types of dementias have different causes, and different clinical courses and prognoses. Some dementias may be arrested or even cured (Randels 1984; Gustafson 1985). Alzheimer's disease and cerebrovascular disease, involving circulation of the blood to the brain, are the leading causes of dementia and are irreversible. They may occur together or in combination with a cause of dementia that can be treated to improve the patient's overall functioning.

Although estimates vary, Alzheimer's disease is recognized as the leading cause of dementia in persons over 65, underlying 50 per cent to 60 per cent of cases. The terms used for Alzheimer's disease in the literature include senile dementia of the Alzheimer's type (SDAT) and presenile dementia of the Alzheimer's type (PSDAT) to distinguish cases according to whether onset occurs before age 65 (PSDAT) or after age 65 (SDAT). Reliable figures on the prevalence of Alzheimer's disease in the population under 65 are not available. The best estimates are that, of all patients with diagnosed Alzheimer's disease, 10 per cent to 20 per cent are aged 45 to 64, with the disease rarely occurring in persons under 45 (Hay and Ernst 1987).

Alzheimer's disease has traditionally been viewed as one condition with late and early onset forms, characterized by a common neuropathology and etiology. However, studies of structural and neurochemical changes in the brains of persons with early onset and late onset Alzheimer's (compared with brains of normal individuals of the same age) indicate a greater variation from the norm occurs with early onset Alzheimer's disease and suggest that there are two distinct forms of the disease, although the question is by no means resolved (Roth 1985; Bondareff 1986).

The second leading cause of dementia is cerebrovascular disease, also called stroke or multi-infarct disease, accounting for about 20 per cent of cases. Multi-infarct disease refers to the group of diseases in which damage to the blood vessels of the brain results in the death of brain tissue (OTA 1988). Dementia may ensue after a certain total mass of brain tissue is destroyed by a single large stroke or series of smaller strokes. Diseases of the blood vessels and arteries in the brain were thought to be the leading cause of dementia in the elderly until the late 1960s and early 1970s, when autopsy studies found clear evidence of Alzheimer's

disease and no damage to the blood vessels (Cohen and Eisdorfer 1986). The causes of multi-infarct disease are not known, although risk factors such as high blood pressure, diabetes and cigarette smoking have been identified. Patients appear to suffer a series of mini-strokes affecting different parts of the brain, each associated with a specific loss of functioning.

Multi-infarct disease and Alzheimer's disease can occur together and the combination causes an estimated 20 per cent of cases of dementia. The remaining causes of dementia (discussed below) underlie about 10 per cent of cases (Mace and Rabins 1981). Some of these causes are reversible and some are not.

Reversible causes of dementia are listed below (Cohen and Eisdorfer 1986).

o Infections

A major illness accompanied by fever may change the body's metabolism and affect the way an individual behaves. Behaviours such as confusion, lethargy and withdrawal may impair communication, for example, and give the false impression of progressive dementia.

o Disturbance to the body's metabolism

Metabolism can be disturbed by malnutrition, dehydration, a shortage of needed enzymes and minerals and many other conditions that yield physical and mental symptoms.

o Cardiovascular and pulmonary diseases

The amount of oxygen and other nutrients reaching the brain can be impaired by diseases such as severe heart disease, high blood pressure, and arrhythmias that decrease the performance of the lungs, heart and blood vessels.

o Medications

Drugs that frequently have serious side-effects include diuretics used in the treatment of high blood pressure, and drugs taken over a long period, such as digitalis, hormone preparations, and insulin. Drugs taken in combination with other drugs or alcohol can result in memory loss, agitation, or drowsiness.

o Structural damage to the brain

Brain tumors or subdural hematomas (blood clots) caused by a blow to the head or other injury are common causes of structural damage. A psychiatric and neurologic examination can likely determine whether structural damage is responsible for dementia.

o Visual and hearing losses

Sensory impairments may be underestimated as a cause of communications problems and create the impression of memory loss and other deficiencies.

o Depression

Depression embraces a class of psychiatric disorders characterized by many possible symptoms: change in appetite, disrupted sleep, loss of interest in pleasurable activities, irritability and restlessness, or decreased energy and fatigue. Depression can be difficult to diagnose because old people may be reluctant to talk about it and it may accompany disease and alcohol or drug use.

o Social isolation and sensory deprivation

People with few social contacts can become withdrawn, confused and disoriented, creating the impression of dementia.

Dementia can be caused by various infections, such as syphilis, meningitis or tuberculosis. However, the virus for acquired immune deficiency syndrome (AIDS) appears to be the leading cause of dementia from infection (OTA 1988). AIDS causes dementia through two mechanisms. First, damage to the immune system caused by the human immunodeficiency virus can lead to brain infections by other organisms. Also, the virus appears to attack brain cells directly; autopsies of persons who die with AIDS-related dementia show clusters of immune cells in some areas of the brain, affecting primarily cells deep in the brain rather than the cerebral cortex. Probably most persons with AIDS show signs of dementia, in most cases caused directly by the virus.

It is not yet known whether dementia occurs in persons who test positively for antibodies to the virus but do not show signs of AIDS or the AIDS-related complex (ARC). Research in this area is just beginning, and the full extent of AIDS dementia will not be known until the research progresses and more data are accumulated.

Dementia may also be caused by degenerative diseases such as Huntington's disease and Parkinson's disease, and auto-immune diseases such as lupus erythematosus (Mace and Rabins 1981). There is also some evidence that various psychosocial factors (i.e., acute trauma, cultural values, personality traits) have a role in the initial development of dementia (Henry 1986).

The conditions causing dementia are difficult to diagnose, particularly at the early stages, since the symptoms are similar. A definite diagnosis of Alzheimer's disease is possible only through a brain biopsy or autopsy to ascertain the presence of structural changes characteristic of the disease. The size and weight of the brain are reduced by Alzheimer's disease, although the diagnosis rests on microscopic examination of brain tissue for anatomical lesions called neurofibrillary tangles and neuritic plaques. These lesions are also found in small numbers in the brains of older persons without dementia, and thus diagnosis is based on the density of these structures.

Chemical changes in the brain are also associated with Alzheimer's disease. Nerve cells in the brain, or neurons, communicate through a combination of electrical impulses and a large number of chemical substances, or neurotransmitters. The neurotransmitter called acetylcholine appears to be affected by Alzheimer's disease. Autopsies have found that tracts of neurons containing acetylcholine (cholinergic tracts) show significant loss of cells. Before the cells die, their ability to produce acetylcholine is greatly reduced, particularly in areas of the brain with concentrations of neurofibrillary tangles and neuritic plaques. These findings have prompted research on drugs that affect the supply of acetylcholine in the brain, although none has shown long-term effectiveness. Also, it is not possible to say that cholinergic changes cause Alzheimer's disease, anymore than the characteristic tangles and plaques cause it. Rather, a cause or causes for these changes must be discovered (Cohen and Eisdorfer 1986).

2.2 Etiology of Alzheimer's Disease

Research on the cause or causes of Alzheimer's disease has pursued several channels, on the theory that intervention strategies can be developed once the cause is known. The key lines of inquiry are summarized below.

o Genetic studies

Several studies of the families of persons with early or late onset Alzheimer's disease have found a greater prevalence of the disease among kin than is found in the general population. Methods and definitions used in the studies vary and preclude comparison of results. By way of example, one study found the risk of the disease among 3426 relatives of 377 persons with Alzheimer's disease was 4.3 times as great as in the general population (Cohen 1984).

Alzheimer's disease also appears with above-normal frequency in persons with Down's syndrome who live into their fourth and fifth decade. Also, relatives of persons with Alzheimer's disease have about three times the incidence of Down's syndrome than expected in the general population, further suggesting a genetic link (Terry 1985).

o Virus etiology

The discovery that kuru and Creutzfeldt-Jakob disease, both of which lead to dementia, are caused by a slow virus spurred investigations for a viral cause of Alzheimer's disease. Experimental attempts to inoculate primates with specimens from persons with Alzheimer's disease have found no evidence that the disease can be transmitted. Research on a viral cause for Alzheimer's disease now tries to link it with Creutzfeldt-Jakob disease on a common pathogenetic basis (Lauter 1985), or examines similarities with scrapie, a disease in sheep transmitted by a virus-like particle that produces brain changes similar to those found in Creutzfeldt-Jakob disease (Cohen and Eisdorfer 1986).

o Metallic toxins

Elevated levels of aluminum and silicon have been found in neurofibrillary tangles and neuritic plaques in the brains of persons with Alzheimer's disease. The role of aluminum and silicon is uncertain, however. More research is required to determine whether deposition of these materials is a cause or a consequence of Alzheimer's disease (Mace and Rabins 1981; OTA 1988).

o Alterations in the immune system

Certain antibodies are found in abnormal levels in brain tissues of persons with Alzheimer's disease, suggesting several lines of inquiry. Are these antibodies formed to counter a virus

that causes Alzheimer's disease, or are they produced in the course of the disease to attack and destroy brain tissue (Cohen and Eisdorfer 1986)?

o Polypeptide changes in the hypothalamus

Persons with Alzheimer's disease exhibit a deficit of neuropeptides, chemicals produced by the hypothalamus that affect the action of other neurotransmitters. Research on polypeptides is just beginning but may explain why simple replacement of acetylcholine is not an effective treatment (Cohen and Eisdorfer 1986).

2.3 Symptoms and Stages of Alzheimer's Disease and Related Dementias

Memory loss and disorientation are often the first signals alerting an individual or a family to the need for professional help. Once a diagnosis of dementia has been made, families often can recall from earlier years incidents of unexplained or even bizarre behaviour, or personality changes, that may have been related to early stages of dementia (Chenoweth and Spencer 1986).

Early diagnosis of Alzheimer's disease is difficult because initial signs are hard to pinpoint, onset is subtle and gradual and many patients do not see a physician in the early years of the disease. Alzheimer's disease is also difficult to diagnose because its symptoms are similar to those of dementias from other causes. Patients may be suffering from various physical ailments or more than one cause of dementia; for example, estimates of the coexistence of depression and Alzheimer's disease range upwards from 30 per cent of all cases of dementia (Marco and Randels 1984). Despite these difficulties, autopsy studies indicate that clinical diagnoses of Alzheimer's disease are 70 per cent to 85 per cent accurate (Hay and Ernst 1987).

Procedures used to diagnose dementia depend on the physician or hospital involved but can include neurologic and physical examinations; various laboratory tests such as blood chemistry tests and thyroid studies; and a mental status examination revealing problems with functions in different parts of the brain. It may also include a lumbar puncture (spinal tap) to rule out an infection or other abnormality of the central nervous system, an EEG (electroencephalogram) recording electrical activity in the brain, and a CT scan (computerized tomogram) and an MRI (magnetic resonance imaging) that produce a picture of the brain and any evidence of stroke, tumors, or other underlying causes of dementia (Mace and Rabins 1981).

A diagnosis of Alzheimer's disease is made after all other possible disorders have been eliminated, and the symptoms observed over time appear compatible with clinical descriptions

of the illness. Criteria that lend credence to a diagnosis of Alzheimer's disease include (Lauter 1985):

- Time - some symptoms have been apparent for several years.

- Progression - the behaviour and symptoms indicate steady deterioration.

- Depression - the patient does not exhibit behaviour, or have a family history, associated with depression.

- Etiology - no other specific agents can be identified by test results (or other evidence) as being a cause of the dementia.

- Other brain diseases - the clinical history is not compatible with other brain disease, of unknown cause.

A diagnosis distinguishing between cerebrovascular (or multi-infarct) disease and Alzheimer's disease may be difficult, since the differences in symptoms are subtle. Whereas Alzheimer's disease is characterized by a gradual, imperceptible decline, cerebrovascular disease follows a more variable course. The patient may show no change for extended periods, or even some improvement. A series of mini-strokes may then cause a further loss of function. The overall picture is thus one of decline marked by step-wise progression or a series of improvements and declines (Mace and Rabins 1981; Cohen and Eisdorfer 1986).

The symptoms of Alzheimer's disease vary from patient to patient and may change from day to day in an individual. In a study in Quebec, Dastoor and Cole (1988) showed considerable inter-individual variation in which functions deteriorated among 13 physically healthy, psychotropic free patients, although overall scores on the Hierarchic Dementia Scale declined consistently and progressively over the four years for all patients. The final stages may be reached in 10 years, or 10 months. Hay and Ernst (1987) report European studies that show a median or mean survival time of five to eight years from onset of the disease, with US studies showing a median or mean time of eight to 10 years. From the date of diagnosis, the median or mean survival time is three to four years. Women with Alzheimer's disease live one or two years longer from onset than do men. No symptom is reliably predictable, although the loss of recent memory seems universal. If there are no other ailments, a patient with Alzheimer's disease can remain physically strong for years. Thus, the period of home care for

patients with Alzheimer's disease can be longer than the period of home care for the physically frail elderly.

Various stages of Alzheimer's disease have been defined. For example, Reisberg (1987) identifies seven stages to aid in diagnosis and on-going assessment of the disease. Morscheck (1984) describes four common stages of the illness. In stage one, initial symptoms are subtle. Incidents of forgetfulness are indistinguishable from the normal consequences of fatigue, overwork, anxiety or the onset of a head cold. Eventually, however, a particularly unusual event will alert the family - if not the patient - that something is wrong. The patient will forget to put on an article of clothing before leaving the house, or prepare to eat the same meal twice, or wander away from home and be unable to find the way back.

In stage two, multiple functional decline becomes more apparent and intensifies in stage three. Commonly:

- Memory deteriorates. Recent memory is lost, and many patients appear locked in their childhood years.
- Language deteriorates. Patients have trouble recalling single words or expressing thoughts. They may be able to read, but without comprehension (Mace and Rabins 1981). They may not understand what is said to them; they may become mute or babble incessantly.
- The ability to do simple arithmetic or consider several variables together is lost.
- Agitation and energy levels increase. The patient may pace constantly, or pack and unpack, dress and undress.
- Sleep disturbances occur. The patient may wander about the house for hours and likely requires supervision.
- Total personal care is needed. Gradually, the patient forgets how to eat, dress, bathe, and use the toilet unaided. Incontinence develops.
- The patient may forget how to walk.
- Seizures occur in some patients.
- Patients may forget how to swallow. Other eating problems include messiness, inability to gauge temperatures, rigid likes and dislikes, and inability to choose between offered foods (Mace and Rabins 1981).
- Catastrophic reactions occur when the patient is overwhelmed by strange situations, confusion, a task beyond the patient's ability or some other stress, and overreacts with anger, tears, or other emotional outburst.

Throughout stages three and four, the patient shows marked changes in personality to the extent that the "real" person is lost. Patients may undergo extreme mood swings, or become suspicious or abusive.

Stage four is the terminal stage of Alzheimer's disease, although it may last for several months. Some patients lie in a fetal position, oblivious to their surroundings, while others are extremely agitated. There is no physical pain attributable to Alzheimer's disease, although other conditions present may be painful. Reisberg (1987) notes that Alzheimer's disease is not generally noted on death certificates as a cause of death, and thus some other cause is usually ascribed.

There is no known cure for Alzheimer's disease. Drug treatments for the primary symptoms of memory loss, confusion and disorientation remain experimental and of uncertain value.

Drug treatments for secondary symptoms, such as hostility, hallucinations and depression, can be effective and may relieve some of the demands on caregivers. However, drugs affect old people differently than the general population and dosages must be carefully monitored and adjusted over time (Petrie 1985; Cohen and Eisdorfer 1986). Some symptoms may be better treated through patient management. For example, night wandering may be controlled by a program of daytime exercise, restricted napping, comfortable nighttime sleep arrangements and other such strategies, rather than by use of sedatives that may increase daytime confusion and fatigue (Mace and Rabins 1981).

Effective treatment and care of the patient with Alzheimer's disease requires recognition of the variable pace of the disease and its effects on the patient's capabilities (Cohen and Eisdorfer 1986, 143):

> While Alzheimer's disease involves the slow, irrevocable loss of ability and ultimately even the sense of self, the stereotypical notion that victims of dementia lose overnight the ability to think, write, read, talk, work or love is a tragic error. Changes do occur, but skills and abilities decline at different rates. In fact, some skills and feelings remain relatively preserved for many years.

3.0 PREVALENCE OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS IN ONTARIO

An understanding of the number of cases of Alzheimer's disease and related dementias in Ontario -- the prevalence -- is a key to health and social services planning. The number of old people in Ontario and the numbers of "old" old people (over age 75), who are particularly likely to develop dementia, are increasing. The public cost implications of decisions on modes of treating dementia are substantial and, as Stone (1986) suggests, an unprecedented increase in the numbers of dementia patients and the costs of caring for them could trigger a societal evaluation of values and distribution of resources.

Despite the importance of accurate data, no comprehensive studies of the prevalence of either Alzheimer's disease or dementia in Canada were available during the study period. Studies undertaken elsewhere examine the prevalence of dementia, and not Alzheimer's disease, because of the difficulties of obtaining an accurate diagnosis of the disease. Most focus on persons aged 60 and older, because of the relative rarity of dementia in younger populations (DCP 1985). As well, most address only moderate and severe cases of dementia because mild dementia is difficult to define; as a diagnosis, it is often incorrect and is a poor predictor of a subsequent diagnosis of moderate or severe dementia in a patient (Lauter 1985).

Differences in definitions of dementia in various studies and other methodological issues make it difficult to compare prevalence studies from other countries to obtain a single set of rates that can be applied to Ontario populations. Despite methodological differences, however, various studies yield prevalence rates that cluster in narrow bands, and increase with age. Preston (1986) found significant levels of agreement on prevalence rates in seven studies that used comparable methodologies and, through regression analysis, developed a formula for rates that forms a good "fit" with the findings of the comparable studies. Rates developed by Preston (1986) will be used here to estimate the prevalence of dementia in Ontario. Because these rates are available for various cohorts in the 65 and older population, the effects of changes in the aging population can be illustrated.

As a point of comparison, prevalence estimates by Jeans et al. (1987) based on a survey of institutionalized elderly in Ontario will also be discussed. Finally, initiatives by the federal government to improve the information of prevalence of Alzheimer's disease will be presented.

3.1 Estimate One - Prevalence Based on Rates from Comparable Studies

Preston (1986) derived prevalence rates from seven studies that shared the following features:

- interviews or standard instruments were used to diagnose dementia;
- mild cases were excluded from the study;
- institutional and non-institutional populations were included;
- only point estimates or studies of less than one year's duration were included; and
- only studies of the whole population potentially at risk were included, thus excluding studies based on case registers and general practice consultations.

Prevalences derived from the studies were:

Age Group	Prevalence per 1000 Population
65 to 69	17.8
70 to 74	33.4
75 to 79	62.6
80 to 84	117.4
85 to 89	220.2
90 and over	413.0

(Source: Preston 1986, 264)

Exhibit 3.1 shows that the population aged 65 and older in Ontario is forecast to increase by 38 per cent between 1988 and 2001.

Exhibit 3.1 Population Projections for Ontario, 1988-2006

Age Group	Projected Population (1000's) 1988	2001	2006
65-69	377.0	428.2	451.3
70-74	279.3	390.3	390.3
65-74	**656.3**	**818.5**	**841.6**
75-79	207.5	319.1	331.3
80-84	126.7	197.8	241.8
85-89	63.0	109.0	124.3
90+	28.5	48.3	59.1
75+	**425.7**	**674.2**	**756.5**
TOTAL	1082.0	1492.7	1598.1

Source: M.V. George and J. Perrault. Population Projections for Canada, Provinces and Territories 1984-2006. Statistics Canada 1985. Catalogue 91-520.

Notes: Figures are taken from a low-growth scenario, used by Statistics Canada to discuss the growth and structure of the population 65 and older. There is little difference among the various growth scenarios in the number of people 65 and older.

Although the most rapid growth occurs in the 65-to-74-year age group, after 2001 the group aged 75 and older begins to increase more rapidly. Between 2001 and 2006, the population aged 75 and older increases by 12 per cent, compared with a 3 per cent increase in the 65-to-74-year age group. The population aged 75 and older also forms a larger proportion of the elderly population, increasing to 47 per cent of the total in 2006 from 39 per cent in 1988.

Exhibit 3.2 shows there are an estimated 69,550 cases of moderate and severe dementia in the Ontario population aged 65 and older. This number represents 6.4 per cent of the estimated 1988 population in this group, a prevalence compatible with rates for dementia in the range of 5 per cent and 7 per cent reported elsewhere (Lauter 1985; Bergmann 1985).

The number of women with dementia is estimated at 45,200, or about 65 per cent of the total,[1] as women live longer than men and the prevalence of dementia increases with age (Gurland 1984). Most cases -- 77 per cent in 1988 -- involve patients aged 75 or older.

The number of cases of dementia is forecast to increase by 55 per cent between 1988 and 2001, barring any major advances in prevention or treatment. This increase reflects both the increase in the population aged 65 and older and, within that population, increases in the older groups with a higher prevalence rate. Increases in prevalence rates among the population 65 and older also reflect the increase in the older groups. As suggested by Stone (1986), prevalence will also increase in the future if increasing numbers of men live to advanced ages that carry a high risk of dementia.

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[1] The estimate was prepared by multiplying the number of cases of dementia in each age cohort by the percentage of women in the cohort.

Exhibit 3.2 Estimated Prevalence of Moderate and Severe Dementia in Ontario, 1988-2006.

	Estimated Number of Cases		
Age Group	**1988**	**2001**	**2006**
65-69	6710	7622	8033
70-74	9329	13036	13036
65-74	**16039**	**20658**	**21069**
75-79	12990	19975	20739
80-84	14875	23222	28387
85-89	13875	24002	27371
90+	11771	19948	24408
75+	**53511**	**87147**	**100905**
TOTAL	69550	107805	121974
Prevalence in population 65 and older	6.4%	7.2%	7.6%
65 to 75	2.4%	2.5%	2.5%
75+	12.6%	12.9%	13.3%

Source: The DPA Group Inc. 1988. Estimates based on projected populations presented in Exhibit 3.1 plus prevalence rates calculated by Preston (1986).

3.2 Estimate Two - Prevalence Based on Extrapolation from an Institutional Survey

A province-wide survey of the institutionalized elderly in Ontario provides the basis for estimates of prevalence in the province prepared by Jeans et al. (1987). The survey included 2391 individuals aged 65 and older who were tested on the Multidimensional Observation Scale for Elderly Subjects (MOSES), which measures cognitive and interpersonal functioning.[2] The MOSES data formed the basis of an estimate that 22.35 per cent of elderly institutionalized people in Ontario are severely disoriented or demented (score of 25 or higher out of a possible 32 on the Disoriented Behaviour Scale of MOSES)[3]. An estimate of the number of severe dementia cases in institutions and in the community could then be obtained through calculations based on a ratio of institutionalized dementia cases and cases in the community.

Reviewing a study by Nielsen (1963) of ratios between community-dwelling and institutional dementia patients, Jeans et al. (1987) selected a ratio of 2:1 for Ontario but caution that the applicability of the ratio is uncertain because various studies have found ratios of 1:1 to 6:1. Preston (1986) observes that levels of institutionalization vary by country and by time, thus making it difficult to adopt a finding from one study for use in another situation.

Starting with an estimate of severe dementia in the institutionalized elderly, Jeans et al. (1987) calculated the total number of institutionalized elderly with severe dementia. A ratio of 2:1 was then used to calculate the number of cases of severe dementia among the elderly in the community. The number of institutional and community cases thus obtained indicated a prevalence rate for severe dementia of 5.23 per cent among the Ontario population aged 65 and older. Reworking the calculations to include both moderate and severe cases (18/32 on the Disoriented Behaviour Scale), the authors derived a prevalence rate of 10.2 per cent among the elderly population in general and 43.5 per cent among the elderly in institutions.

The rates developed by Jeans et al. (1987) thus suggest there are about 56,600 cases of severe dementia in the estimated 1988 Ontario population 65 and over and 110,400 cases of moderate and severe dementia.

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[2] MOSES was developed over several years by E. Helmes, Ph.D. at the London Psychiatric Hospital with funding from the Ontario Mental Health Foundation. The major data collection exercise occurred in 1980, with use of the scale increasing through word-of-mouth and publication in 1986. The scale is now used at London Psychiatric Hospital, at hospitals in Toronto and Ottawa, and in various facilities outside Ontario (Helmes 1988, personal communication).

[3] The Disoriented Behaviour Scale assesses speech and its comprehension, ability to find one's way in a building, recognition of staff and awareness of time and place.

3.3 Summary of Estimates of Prevalence

The two estimates of the prevalence of dementia among the elderly have been presented: a rate of 6.4 per cent for persons 65 years of age and older, based on comparable studies (estimate one); and a rate of 10.2 per cent for the same age group, based on an extrapolation from an institutional survey (estimate two).

	Prevalence in Elderly Population	Cases in Ontario, 1988
Estimate One - Rates from Comparable Studies	6.4%	69,550
Estimate Two - Extrapolation from Institutional Survey	10.2%	110,400

Estimate two yields only a single rate for the population 65 and older and therefore cannot be used to estimate the number of cases in the future. The effects of increases in the proportion of old people 75 years and older, who have a higher prevalence of dementia, would not be captured by a single prevalence rate for the 65 and older population. Estimate one, based on prevalence rates for five-year age cohorts, suggests the number of cases of dementia among the elderly in Ontario will increase from an estimated 69,550 in 1988 to 121,974 in 2006, an increase of 55 per cent, barring any advances in prevention or treatment.

3.4 Current Studies as a Basis for Prevalence Estimates in Future

Two initiatives by the federal government in Canada promise to improve the base for estimates of prevalence throughout the country. The first -- the Health and Activity Limitation Survey-- was undertaken by Statistics Canada, and data gathering is now complete. The second is just being launched by the Laboratory Centre for Disease Control of Health and Welfare Canada.

In the June 1986 census, Statistics Canada included a two-part question on disability: "Are you limited in the kind or amount of activity that you can do because of a long-term physical condition, mental condition or health problem and do you have any long-term disabilities or handicaps?" Those within households who answered "yes" and a sample of those answering "no" were followed up immediately, and a survey of individuals in institutions was conducted in the spring of 1987. Wherever possible, the individual who had reported a disability was

interviewed in an attempt to elicit the type and severity of limitation, the underlying health condition, the types of aids used to carry out everyday tasks, the barriers to education, employment, accommodation, transportation, and leisure as well as the out-of-pocket expenses. Caregivers provided information on disabled persons who could not answer the questions.

Highlights of the data are to be published in the fall of 1988, and the Statistics Canada office for the Health and Activity Limitation Survey is willing to meet special requests for analysis of the data (Furrie 1987). An estimate of time and cost for the searches will be provided within two weeks of receipt of the request. Although the data cannot show numbers of people with Alzheimer's or related dementias, they do indicate the nature of disability and they clarify the prevalence of disabilities in general among the elderly.

For example, in the group aged 65 and older, 45.5 per cent reported having a disability and of this group, more than three-quarters reported multiple disabilities. This suggests a total 1,221,995 seniors are disabled in one way or another. Of every 100 seniors (65 years and older) reporting a disability, 30 indicated their activities were limited "because of a learning disability or emotional or psychiatric disability". This category includes persons with dementias. The statistics indicate that 16 per cent of disabled seniors reside in institutions or homes for the aged -- rising from 4.5 per cent of 65 to 69 year olds to 42.7 per cent of the group 85 and older. Disabled seniors in institutions or homes for the aged represent about 7 per cent of all seniors.

A refinement of the questions being asked during data analysis could provide another means of estimating the prevalence of Alzheimer's disease and dementias among the elderly in Ontario, especially if supplemented by results from the epidemiological study on the drawing boards in the Laboratory Centre for Disease Control.

LCDC, working with a group from the University of Ottawa, will be coordinating efforts at five centres across Canada to determine the incidence, prevalence as well as causes of Alzheimer's disease, first, and of osteoporosis, later. The study will be funded through the National Health Research and Development Program from the $4 million annually that is to be set aside by the government for research on diseases affecting the independence of seniors. The research monies are part of a larger promise, made in February 1988 by Minister of National Health and Welfare Jake Epp, to spend an additional $30 million each year to improve the quality of life for seniors in Canada (Canada, Health and Welfare 1988a).

4.0 THE NEEDS OF DEMENTIA PATIENTS AND THEIR CAREGIVERS

4.1 Introduction

Much of the literature on the needs of dementia patients living in the community and their caregivers reports on attempts to measure and describe the kinds of stresses or burden experienced by caregivers. "Burden" is the term frequently used to embrace the physical, psychologic or emotional, social and financial problems that may be experienced by family members caring for a dementia patient (George and Gwyther 1986). The findings of these studies are contradictory in some areas; for example, there is no agreement among various studies on whether caregivers have health problems as a result of caregiving. Such differences in findings are caused to some extent by methodological limitations and differences between studies. They also reflect the fact that caregivers experience different kinds and levels of burden, depending on individual circumstances, and both circumstances and burden change over time.

Much of the more recent research is more explanatory than descriptive, examining the kinds of variables that affect such aspects of caregiving as caregivers' sense of burden, use of support services, and plans to institutionalize their patient (Pringle 1988). Again, findings are sometimes contradictory, although there is general agreement that burden does not vary directly with the patient's condition or behaviour.

The most consistent policy recommendation arising from the literature on the needs of patients and caregivers is that a range of services be made available throughout the course of the patient's illness on an as-needed basis. Apart from this and a few other more detailed observations on implications for practice presented in subsequent sections, most studies do not conclude with specific program recommendations.

The needs of the dementia patient living in the community are addressed in the literature in a different fashion and to a much lesser extent than the needs of caregivers. Patient needs are viewed in terms of appropriate physical treatment, although some work discusses the psychologic and emotional needs early in the illness. Recently, some discussion has begun on the legal needs and rights of impaired elderly persons (Working Group on Legal Issues 1987), and the governments in Canada are being urged to revise badly outdated legislation. A Committee on Guidelines for Comprehensive Services to Elderly Persons with Psychiatric

Disorders, convened by the Department of National Health and Welfare, called for improved criteria, definitions and procedures in the determination of competence or incompetence; the initiation and monitoring of surrogate management; standards of care; and advocacy (Working Group on Legal Issues 1987). The Committee noted that Alberta's Dependent Adults Act of 1976 incorporated some desirable changes but most provinces were far behind. "Too often a presumption of incompetence is made (with or without formal recourse to legal procedures) on the basis of age alone, on the grounds of psychiatric illness or physical frailty or because of 'difficult' behaviour while in institutional care...Competence has not been well defined in law: no court decision has yet produced a specific definition; no formal guidelines exist, and no detailed and standardized assessment information is required to reach a conclusion of mental incapacity...In Ontario,...only one psychiatrist's assessment is required for a declaration of incompetence, and admission to hospital is not a prerequisite."

Limitations of research on patients' needs are not discussed in the literature. Emphasis in the literature on the caregiver may reflect the fact that, in practice, the patient is served by measures that support the caregiver. In the absence of specific medical treatment for Alzheimer's disease or formal rehabilitative programs, the care and well-being of the patient is largely the responsibility of the caregiver. Efforts to support the caregiver in the caregiving role thus also help maximize the health and functional ability of the patient (Barnes et al. 1981). Also, interventions with the caregiver and the family may be more effective than interventions with the patient. While dementia may limit the patient's ability to compensate for debility, the caregiver and family can learn new techniques for coping with problem behaviours and other sources of stress (Zarit and Anthony 1986).

The needs of caregiver and patient are not always complementary, however. Although it is generally recognized that most patients fare better at home than in institutions and most families prefer home care for relatives, the long-term toll of home care is substantial. Wasow (1986, 96) comments:

> The present trend is to encourage caregivers to stick with caregiving until they are exhausted on all fronts. But then there are two victims at the end of the long seige with Alzheimer's disease: the patient, dead from Alzheimer's disease, and the caregiver, totally exhausted--emotionally, physically and financially.

The needs of caregivers and their patients must therefore somehow be balanced such that supports are offered for each group.

The following sections discuss:

. the needs of dementia patients;

. limitations of studies of the needs of caregivers;

. the needs of caregivers; and

. implications for programs for dementia patients and caregivers.

4.2 The Needs of Patients with Alzheimer's Disease and Related Dementias

Little research has been done on the quality of the family caregiving environment and its influence on the onset and course of Alzheimer's disease (Ory et al. 1985; Niederhehe and Frugé 1984). Niederhehe and Frugé (1984, 7) comment:

> On the whole, it appears preferable for impaired older persons to remain in a familiar home setting amid family relationships, as long as these are positive and the needs of neither the elder nor the other family members are being overlooked. We have had little balanced research which has examined the quality of the family context in a balanced, neutral fashion, neither stereotyping it as troubled, burdened and perhaps rejecting of the elder, nor romanticizing it as always positive and caring.

Much of the research on patients focuses on physical treatment and patient capabilities. Fisk and Pannill (1987), for example, found that community-dwelling patients with Alzheimer's disease are not as disabled as commonly supposed, having only moderate reductions of cognitive functions and physical activities of daily living (i.e., feeding, dressing, ambulation). The researchers found in a two-year study of 159 community-dwelling Alzheimer's disease patients that the patients each had an average of 3.4 other medical problems, primarily gastrointestinal, cardiac and hypertension problems commonly found in elderly populations. Appropriate treatment of medical illness was critical to maintaining the patient at home, as was elimination or reduction of medications that may have been contributing to the patient's confusion. Noting that 45 per cent of the patients lived alone and 39 per cent had not been out of the house during the previous week, the researchers found isolation to be a major problem for these patients.

Resource books for caregivers, such as Mace and Rabins (1981) The 36-Hour Day and Cohen and Eisdorfer (1986) The Loss of Self, outline problems the patient experiences in the course of dementia, such as problems with speech and communication, coordination, and sense of time, as discussed in Section 2.0. Mace (1986) recommends that Alzheimer's disease patients

receive on-going physical assessments to identify limitations and remaining skills. Too often, once a diagnosis of Alzheimer's disease has been mad health workers no longer thoroughly assess new symptoms.

Cohen and Eisdorfer (1986) counsel that, during the years of illness, every effort should be made to maximize the patient's ability to function; dementia should not be a deterrent to appropriate treatment. In particular, there is a need to identify and stabilize treatable disabilities: chronic conditions, such as rheumatoid arthritis; conditions such as loss of muscle tone that reduce mobility; and psychiatric illnesses. As well, the patient needs social rehabilitation through contacts with friends and other people, and rehabilitation to maximize life-skills such as eating and dressing.

Various therapies such as behaviour modification, reality orientation and psychotherapy have been used to treat dementia patients, particularly in institutional settings. Often the goal of these therapies is to effect an improvement in terms of the patient's mood or activities. Zarit and Anthony (1986) caution that these outcomes may reflect desires of the staff or families more than those of the patients. Medical professionals must ask whether a particular intervention is treating some aspect of dementia and not simply undoing the negative effects of some other intervention or aspect of the patient's environment. For example, behaviour modification to improve incontinence is inappropriate if the root of the problem is the patient's inability to find the bathroom.

Although the literature search yielded little on the psychological and emotional needs of the patient, Cohen and Eisdorfer (1986) keep these needs foremost throughout their book. The authors write, for example (Cohen and Eisdorfer 1986, 64):

> Perhaps the most important concern of many patients is the need to participate as actively as possible for as long as possible. They want to have the information to make decisions relating to what is happening to them. Often patients voice this concern because they feel excluded from the family's decision making too soon.

Many patients also want to discuss what the illness means to themselves and their families, although cognitive losses plus speech and language loss may make it difficult for all parties. They fear their confused mental state will deprive them of the ability to relate to their family with dignity and self-respect.

4.3 Limitations of Studies of Caregivers' Needs

Study limitations concern the size and composition of study samples, use of controls, and the use of burden or other single measures of caregiver needs.

o Sample size and composition

Many researchers recruit their samples through local hospitals or self-help groups for caregivers to patients with Alzheimer's disease or other dementias. Samples are therefore small; a review of 39 prominent studies noted that 17 had samples of fewer than 50, and six had samples of 51 to 100 (Pringle 1988). Since samples are chosen from groups of individuals who sought help for themselves or a patient, they are not representative (Gwyther and George 1986): they often have above-average levels of income and education and do not include proportionate representation of various racial groups.

Some study samples include caregivers to physically disabled patients and cognitively-impaired patients, and are not restricted to caregivers of dementia patients. Such studies may fail to capture any stresses on caregivers arising from the patient's loss of cognition, as distinct from stresses arising from any physical disability, and thus may not fully examine the needs of caregivers of dementia patients (Niederhehe and Frugé 1984).

Finally, research programs that entail measurement at two points in time may encounter difficulties in retaining sample members. The caregiver or the patient may become too ill to participate in a second phase of a study, or changes in the caregiving situation, such as institutional placement, may disqualify the subjects (Mohide 1988, personal communication).

o Use of controls

Haley et al. (1987) observe that few studies have compared the psychological, social and health functioning of caregivers with that of a control sample. Since many caregivers are elderly, it is important to distinguish between the effects of aging and the effects of caregiving through use of controls.

o Summary measures

Some studies examine caregiver well-being as captured in a single summary measure, such as burden, while in reality caregivers may experience stress along various dimensions such as physical health or social support. The caregiving experience and associated needs may be too multi-dimensional to capture with one measure (Haley et al. 1987, Niederhehe and Frugé 1984).

o Measurement instruments

Scales and instruments used to measure caregiver burden are essential to the evaluation of programs and strategies designed to relieve it. However, there is no evidence that these instruments are responsive to true decreases in burden (Pringle 1988). An example of the development of a measurement instrument is provided by Mohide et al. (1988). Mohide et al. (1988) developed the Caregiver Quality of Life Instrument (CQLI), which uses Torrance's time trade-off technique, and tested it by administering it to 30 caregivers and 10 relatives of well elderly. Results indicated the instrument discriminated among different degrees of caregiver wellbeing using standardized states; it discriminated among subjects living with relatives who had differing levels of health and care requirements; and it was responsive to changes in wellbeing in individual caregivers when respite care became available. The researchers recommend further testing of the instrument's applicability to evaluations of interventions directed at relieving caregiver burden.

4.4 Needs of Caregivers

While some researchers focus on objective measures of caregiver burden, others seek explanations as to why burden is experienced so differently by different caregivers. Wasow (1986, 96) comments:

> One of the most striking features of the clinical experience of facilitating groups [for caregivers] and of reviewing the available research is the tremendous variability in the nature and sequence of caregivers' emotional reactions and coping abilities as they attempt to deal with Alzheimer's disease.

4.4.1 Measures of caregiver burden

This section begins with a review of studies that measure caregiver burden, followed with discussion of factors that mediate burden.

Measures of burden among caregivers compared with control groups of non-caregivers were made by Haley et al. (1987) and George and Gwyther (1986). Compared with the controls, caregivers in both studies reported lower levels of life satisfaction; Haley et al. (1987) also found higher levels of depression among caregivers while George and Gwyther (1986) found indicators of poor mental health, with caregivers averaging nearly three times as many stress symptoms as the controls, and a higher proportion (28 per cent compared with 19 per cent) reported using psychotropic drugs. Caregivers in both studies reported substantially lower levels of social activity, such as relaxing, church attendance, time for hobbies, and holidays. Haley et al. (1987) found that activities requiring time away from the patient were particularly affected. By objective standards, caregivers' social networks were as extensive as those of non-caregivers in terms of the number of friends and the frequency of contacts; many continued to receive frequent, brief visits from family and friends. However, caregivers were less satisfied with their networks, perhaps because their needs were greater.

Findings concerning caregivers' health are not unanimous. George and Gwyther (1986) found the physical health of caregivers to be similar to that of the control group, with no evidence of increased use of medical services and no self-rating of poorer health. The researchers commented that their data were group data, which by their nature do not show individuals' circumstances, and that indeed there are caregivers who experience health problems as a result of caregiving although as a group, caregivers are no different from non-caregivers.

Haley et al. (1987) indicate it is not clear from their health data whether caregivers are in objectively poorer health, or whether they are simply more concerned about it. The caregivers used more prescription drugs (unspecified) than the control group and sought medical care more frequently. The researchers concluded that health problems were significant for some caregivers, and commented that overuse of medical facilities and subjective impressions of poor health often are manifestations of stress. Pratt et al. (1985) found that 79 per cent of caregivers in their study (n=240) reported that caregiving had negatively affected their health, and that the 44 per cent of caregivers reporting their health as fair or poor also had significantly higher burden scores than other caregivers.

Financial problems of caregivers and a control group were studied by George and Gwyther (1986), who found that, as a group, caregivers do not experience decreases in financial security relative to the community. However, a study of 150 caregivers in the U.S.A. caring for an Alzheimer's disease patient found 45 per cent reported financial difficulties stemming primarily from medical expenses and home care expenses (Ferris et al. 1987). The 109 caregivers whose patients lived in an institution reported average nursing home costs of $40,000 annually; of the remaining 41 caregivers, whose patients lived in the community, almost half reported costs of $10,000 annually for auxiliary help.

In Canada, caregivers do not seem to experience comparable financial burdens. Interviews with 103 caregivers of frail elderly persons in Ontario found that only 22 per cent used a portion of their family income to support their elderly relatives. Of the remaining 77 per cent, about half reported spending some of their family income on the provision of care, although these expenditures were described as minor in most cases. "It is probably the combination of government benefits to the elderly and the Ontario Health Insurance (and related medical benefits) that makes the financial cost of family caregiving relatively low, especially when compared to the large costs reported in other countries" (Gottlieb 1987,3).

Mace and Rabins (1981) advise caregivers at the outset of the illness to prepare a financial strategy based on potential costs and resources. Costs include income lost if and when the patient or primary caregiver ceases employment, medical treatment costs, expenses incurred by modifying housing to accommodate the patient's disability, and costs of housekeeping and respite care. Resources include provisions under private insurance policies, income tax provisions for caregivers to dependent patients, plus various government-funded services.

Mace and Rabins (1981) also advise that patients prepare a will and make provisions for power of attorney while they are still legally competent. Since patients may forget assets and liabilities, families may have to monitor the patient's mail for bills and search the house for bank books, insurance policies and other evidence of assets.

Laws and legal procedures vary significantly from province to province. In most provinces, for example, power of attorney can be exercised only as long as the donor is mentally competent (Canada, Health and Welfare 1984). (Power of attorney allows one person -- the donor -- to bestow upon another the right to exercise certain, specified property rights such

as banking or property sales on the donor's behalf.) In Ontario, however, changes in the Power of Attorney Act and Mental Health Act effective in January, 1984 allow power of attorney to stand after the donor becomes incompetent. Other legal issues that may face a caregiver include mental incompetency proceedings, contractual liability, medical consent liability and testamentary capacity (concerning wills).

4.4.2 Why burden varies

The experience of burden is shaped by a host of factors related to family relationships, formal and informal supports, individual coping strategies, the character of dementia and the progression of the illness. These factors vary with each caregiver and patient, thus precluding statements about burden and needs that apply to all caregivers. Rather, research in these areas highlights the variability of caregiving and warns against seemingly apparent conclusions. Perhaps most surprisingly, caregiver burden is not directly related to the patient's condition or behaviour (Winogrond et al. 1987; George and Gwyther 1986; Niederhehe and Frugé 1984; Gwyther 1986; Zarit and Anthony 1986). The kinds of factors that seem to affect burden are discussed below.

- Family relationships

Most care of community-dwelling dementia patients is provided by family members. Typically, one individual becomes the primary caregiver, rather than several family members sharing responsibility. The closest relative -- usually the spouse or an adult child -- first assumes the responsibility; more distant relatives become available in a serial fashion reflecting the degree of kinship (Pratt et al. 1985; Niederhehe and Frugé 1984).

Most caregivers are women (Fitting et al. 1986; Niederhehe and Frugé 1984). Many are middle-aged, assuming the caregiving role in addition to responsibilities for paid employment, child-raising and marriage, and thus they experience the stresses caused by multiple roles and responsibilities. Caregivers to spouses often are themselves elderly, experiencing the losses that come with aging along with the demands of caregiving.

There seems to be some agreement that spouses experience more stress as caregivers than do adult children (Jenkins, Parham and Jenkins 1985; George and Gwyther 1986; Caserta et al. 1987; Ory et al. 1985). Fitting et al. (1986) found in a comparison of husband and wife

caregivers that both experience caregiving in similar ways, although young wives (aged 50 to 66) and old husbands (aged 67 to 90) showed the greatest burden. The young wife may have to assume more responsibilities as part of the caregiving role (i.e., new financial responsibilities) and the older husband may have more health-related difficulties. Husbands were more likely than wives to report an improvement in the relationship, perhaps because caregiving marked a new role after retirement and a chance to reciprocate services rendered previously by the wife. Wives were more likely to report a deterioration in the relationship, perhaps because a return to caregiving after the children were grown was unwelcome. Wives generally were more demoralized than husbands, although general measures of burden were the same.

Zarit (1983) as reported in Ory et al. (1985) found husbands reported less burden than wives and may be more effective problem-solvers. Wives typically experienced problems with finances, car repairs and other traditionally male responsibilities, while husbands had more trouble with household tasks. Husbands were more willing to obtain household help, while wives believed they should be able to be both caregiver and housekeeper.

The primary caregiver functions within a larger family network. Pratt et al. (1985) found the family to be a key source of support to the caregiver and a more effective support than a confidant or support group, although respondents in their study noted that the support of the family was not always available. For example, family members, particularly if they cannot accept the diagnosis or the prospect of change in their relationship with the patient, may criticize the primary caregiver.

Niederhehe and Frugé (1984) outline several factors that can shape a family's response to caregiving responsibilities, including:

- the general degree of obligation felt within the family to care for older family members;
- the developmental maturity of the primary caregiver to handle changes in the interpersonal relationship with the patient i.e., the ability of an adult child to accept a parent's dependence;
- the family's ability to handle tensions that may ensue from changing roles in the family and redistribution of power; and

- the pre-existing quality of interpersonal relationships and structure of family life i.e., old rivalries and conflicts may be reawakened by the crisis, or established strengths may be tapped again.

Thus, family roles and relationships can be a source of strength or weakness in a family's response to the stress of dementia in a loved one and may indeed change as a result of the illness.

o Formal and informal supports

Although the family has considerable potential as an informal support to the primary caregiver, formal and informal supports described in the literature do not consistently alleviate caregiver burden. Jenkins, Parham and Jenkins (1985) found the amount of help received from friends, agencies and families was only weakly correlated with burden. The researchers speculated that caregiver needs are so great that the amount of support available is inadequate. Gilleard (1985) also found that caregivers' levels of stress and strain were not related to the amount of help received from other family members or formal support services, or the amount of time the caregiver spent with the patient.

Ory et al. (1985) noted that caregivers' perception of adequacy may be more important than actual levels of help provided. Also, caregivers may be reluctant to ask friends and family for help, among other reasons, to avoid criticism from informal helpers who disagree with their methods. Caregivers may seek formal supports with caution because of concerns about the quality of service and whether it would be available regularly. Also, caregivers are concerned that the patient's behaviour may be disruptive or otherwise unsuited to the program or service.

Some non-users of services in a study by Caserta et al. (1987) noted a similar concern about behaviour plus concern about cost and about leaving their patient with a stranger. However, most non-users of services said they did not need them because their informal supports met their needs, or that their patient was not so impaired that formal supports were required.

Robertson and Reisner (1982) also studied caregivers' knowledge and use of formal support services. In a study of 24 caregivers in Saskatoon, more than one-half expressed a need for respite care and were knowledgeable about local respite services, but few used them. The

researchers suggested that the services were not accessible or did not meet the caregivers' and patients' needs. While most caregivers expressing a need for Meals-on-Wheels, home nursing and social work services received the services, only one-half of those who expressed a need for homemaker service obtained it, suggesting cost of the service was a problem. Finally, few caregivers believed they needed the services of the public health nurse. The researchers commented that this may represent a missed opportunity for surveillance and early intervention by the nurse since both patient and caregiver are at risk.

Neysmith and Lewis (n.d.) found a respite program available to caregivers to cognitively-impaired persons and caregivers to frail elderly was used primarily by the former, even though there were far more caregivers to the frail elderly in the population served by the service. The service was available to all who needed it, without rationing, but only those under the most stress -- caregivers to cognitively impaired persons -- were using it. The researchers commented it was not known whether referrals from professionals, instrumental in about half the caregivers' receipt of service, were made only in the most pressing cases, or whether only the most stressed caregivers followed through. In any event, caregivers reported recognizing a need for respite six months before applying for it.

Wolk et al. (1987) found in a study of 20 caregivers in rural Missouri that informal networks of friends and neighbours, often described as active in rural areas, failed to assist caregivers to any real degree. Although the sample size was too small to lead to conclusions about informal supports, the researchers suggested that rural caregivers and their patients need the same formal supports as their urban counterparts. However, their rural location limits access to services and availability.

This observation is in line with comments by Anne Martin Mathews (personal communication 1988) on the "myth of independence" -- that everyone helps everyone else in rural areas. She noted the myth is a major stumbling block to good programming for rural dwellers as is the attitude that government never does anything positive for rural areas. She maintains that adequate and reliable transportation to and from programs or for services is an essential, and often missing, component in rural programs in Canada where climate militates against participation in almost every activity.

Rural areas of Gloucestershire in the United Kingdom are served by community psychiatric nurses who help elderly people obtain the services they need, in part through home visits.

The nurses provide a range of services, including counselling and advice for the elderly and their families, arranging for respite care and giving medication. The nurses operate a radio car service and can be called out on a 24-hour basis to any part of the county (Nusberg 1984).

Studies of the effects of dementia programs, such as respite programs and self-help groups, yield contrary conclusions; certainly, use of formal supports does not consistently reduce burden. The effectiveness of various types of support services will be discussed fully in Section 6.0.

o Individual coping strategies

Individuals vary in their ability to cope with stress, depending on personal skills and inner resources. Pratt et al. (1985), for example, found lower levels of burden were associated with caregivers who had confidence in their ability to solve or reframe problems; both strategies allow the caregiver to define the stressor as a challenge to overcome or to otherwise change it so that it is easier to accept. Passivity in caregivers was associated with higher levels of burden, suggesting either that high burden leads to passivity or that burden is increased among passive caregivers. Also, seeking spiritual support was associated with lower levels of burden, perhaps because spiritual support provides a basis for controlling the meaning of a problem.

Similarly, Winogrond et al. (1987) found that caregivers' morale improved over a six-month period as they learned more about the disease process and patient management (problem-solving coping) and as they shared their stress with others (emotion-focussed coping).

o The characteristics of dementia

Several aspects of dementia create unique stresses on families and caregivers. A loved one's loss of personality and mental capability is particularly stressful to observe, perhaps even more stressful than the death of the loved one. The constant supervision and physical work required in caring for a dementia patient also pose stresses unique to these caregivers. As well, their efforts may be completely unappreciated by the patient. Dementia patients living at home often believe they have no significant problems in activities of daily living, health

and personal relationships. They may view the caregiver as interfering and manipulative, while the caregiver feels obstructed and unappreciated (Sands and Suzuki 1983).

Certain behaviours of dementia patients are particularly difficult for caregivers to cope with and may threaten their ability to care for a patient. These behaviours include violence, abrupt mood swings, fecal incontinence, overt sexuality, suspiciousness, immobility and catastrophic reactions (Ory et al. 1985; Niederhehe and Frugé 1984). However, George and Gwyther (1986) found the patient's symptoms were correlated with only three of 15 indicators of the caregiver's well-being. They concluded that it is the characteristics of the caregiving situation and the resources available to the caregiver, rather than the condition of the patient, that most directly affect caregiver well-being.

o The course of the illness

Families are stressed throughout the course of Alzheimer's disease, but the stress varies with the phase of the illness and families must continually adjust to new problems. In a longitudinal study of 289 caregivers tending Alzheimer's disease patients, Chenoweth and Spencer (1986) reported a series of problems. Before a diagnosis was made, family members felt confused, angry and rejected by the patient because they could not understand his or her behaviour. Cohen and Eisdorfer (1986), for example, counselled caregivers who interpreted early signs of dementia as the withdrawal of the spouse and impending marital breakdown. Problems surrounding the period of diagnosis included difficulty convincing physicians that the patient was ill, and lack of information on the illness and the behavioural changes likely to occur. The message most families received from physicians focused on the hopeless nature of the disease. Such findings have led to a call for a reorientation of physicians in counselling of families, particularly caregivers (Parhad 1988).

Cohen and Eisdorfer (1986) also reported that provision of care by family caregivers created family stress in some cases and family togetherness in others, plus reduced social contacts, stresses of 24-hour care and other problems discussed previously in this section. When asked what led to institutionalization of the patient, 21 per cent indicated either they or the patient had become ill, and about half cited behavioural problems, incontinence or angry outbursts. (Caregivers could provide more than one reason for institutionalization.) However, almost three-quarters said they had simply become overwhelmed by the job.

Jenkins, Parham and Jenkins (1985) also found burden varied among caregivers of patients at different stages of Alzheimer's disease, with burden peaking among caregivers with a patient at the outset of the disease and among caregivers immediately after institutional placement of their patient. The researchers concluded that while dementia is a progressive process, the experience of burden fluctuates and varies with individual caregivers.

In a similar vein, Winogrond et al. (1987) found that over a six-month period, several caregivers to less-impaired patients experienced increasing levels of stress, and greater stress than caregivers of less-functional patients. The researchers speculated that the caregivers of less-impaired patients were unable during the six months to continue minimizing the disease, and contact with other caregivers and patients provided clear indication of the course their patient would follow and the increasing demands they could expect.

The period surrounding institutionalization of a patient is particularly stressful and does not lead subsequently to significantly reduced levels of burden. In a comparison of caregivers to institutional and home-dwelling patients, George and Gwyther (1986) found the lowest levels of well-being among caregivers to home-dwelling patients, although other caregivers experienced problems with mental health and social participation. Pratt et al. (1985) found no difference in burden scores between caregivers to home-dwelling and institutional patients. They speculated that burden among the latter group is related to guilt over the placement, which may be perceived as a personal failure and may follow years of home caregiving with the aim of avoiding institutional placement.

Another view of changes in stress that occur over the course of the illness examines stages in the caregiver's and other family members' adjustment following a diagnosis. Simank and Strickland (1986), for example, report that many authors have compared a family's experience of Alzheimer's disease with the stages of the grieving process developed by Kubler-Ross: denial and isolation, anger, bargaining, depression, and acceptance. Simank and Strickland (1986) found that families may choose to ignore early warning signs of dementia, and although denial is a normal coping strategy, many families carry it to an extreme and fail to recognize grossly disturbed behaviour. Anger can develop under the demands of continuous caregiving. At some point in the illness, many caregivers feel useless and helpless and some exhibit the symptoms of depression such as a decrease in vitality. As anger and depression decrease, caregivers experience increasing guilt about their anger towards the patient, and any decision to place the patient in an institution. Acceptance may occur once the caregiver understands

the disease process affecting the patient and has found the inner resources and community supports needed to care for the patient.

4.5 Implications for Programs and Practitioners

Studies of caregivers' and patients' needs have yielded the following suggestions for programs and practitioners:

- Practitioners must realize that burden is not based solely on the strain of daily caregiving, and that caregivers do not bounce back when relieved of the caregiving responsibility (Pratt et al. 1985).

- Since caregiver burden is eased by various coping strategies (i.e., problem-solving, confidence in one's abilities), these strategies could be taught through educational programs, counselling, support groups or other programs. Respite alone is not sufficient, since caregivers must return to their problems (Pratt et al. 1985).

- Given the importance of the family's support to the primary caregiver, educational programs should be extended beyond the caregiver to family members, to teach them about the needs of caregivers and patients (Pratt et al. 1985).

- Since the caregiver's ability to cope is affected more by the caregiver's context than by the patient's condition, service providers and clinicians must look beyond the functional status of the patient to support the caregiver adequately. Such things as the caregiver's character, resources and perception of his or her situation must be considered (Gwyther and George 1986).

- Caregivers are heterogeneous and experience greatly different kinds and levels of burden. Therefore, no single program or set of programs will aid all caregivers (Gwyther and George 1986). Rather, Zarit and Anthony (1986) recommend that work with a caregiver and the family begin with an individual evaluation of the sources of burden and identification of those sources that can be modified. A plan can then be prepared in consultation with the caregiver to treat the modifiable sources of burden through various strategies.

- The demands of caregiving will change over time, as the disease progresses and as the caregivers experience changes in their situation (i.e. health, employment, financial status). Caregivers require a mix of service options that can be activated as circumstances dictate (Gwyther and George 1986; Niederhehe and Frugé 1984). Counselling and education by trained professionals must be part of the package (Parhad 1988).

- Caregivers experience a variety of psychologic and social problems, and both must be treated through a variety of interventions. Clinical interventions include individual and family counselling, small group therapy and support groups, while social interventions include respite care, information on Alzheimer's disease and other dementias, legal advice and access to centralized information on community resources (Cole, Griffin and Ruiz 1986).

- Service providers must make special efforts to reach caregivers who need a service but do not use it because of concerns about cost or the patient's behaviour, or reluctance to leave the patient with strangers (Caserta et al. 1987).

- Applied research should be directed at defining the needs of an individual community in handling the effects of dementia. Programs should be planned to complement and supplement available resources in response to community needs, rather than developing programs within the narrower boundaries of geriatrics, social services and other disciplines in isolation (Parhad 1988).

5.0 THE LITERATURE DESCRIBING DEMENTIA PROGRAMS AND RESPITE PROGRAMS

The needs of dementia patients and their caregivers can be served to some degree by a range of programs. Some programs, such as Meals on Wheels, home repairs or referrals to community social services, are available to seniors or the community at large and, although they may be important to the caregiver and the patient, they are not discussed here. Rather, this section focuses on programs intended to meet the unique needs of dementia patients and caregivers.

Recognition of the market potential of specialized programs and services for dementia patients, demands of families and voluntary associations, and the hope that specialized approaches may improve the care of dementia patients have all contributed to the recent development of specialized programs and services in nursing homes and in adult day care and respite programs. Only a few specialized programs exist; a task force of the Office of Technology Assessment in the United States directly identified only 120 specialized nursing home units in the United States, for example, and estimated that fewer than 500 were operating.

The task force's work grew out of a previous OTA report on Technology and Aging in America and was requested by four U.S. Senate committees and three committees of the U.S. House of Representatives. Its report was based on available literature, 40 papers commissioned from outside experts, and extensive interviews, including interviews with representatives of more than 100 nongovernment organizations. The task force found that given the recent development of specialized programs and the limited number available, there was little literature or well-structured research on the subject to inform policy-making. In its own research on specialized programs, the task force relied on anecdotal material, interviews and the opinions of experienced clinicians.

Some of the key issues raised by the task force included:

- What standards should programs meet?
- Is it in the individual's best interest to be segregated?
- What are the advantages and disadvantages of specialization?

Some answers depend on understanding whether the needs of dementia patients are substantially different from those of other chronically-ill elderly persons. The task force commented, "Indeed, some of the changes advocated for specialized dementia care are improvements that would benefit many other long-term care recipients" (OTA 1988, 241).

The task force reviewed the literature on the advantages and disadvantages of specialized programs and summarized the findings, as shown in Exhibit 5.1. Although specialized programs are in a developmental stage, the task force believed the most successful specialized programs in adult day care and nursing homes and other residential settings shared the following goals (OTA 1988):

Exhibit 5.1 Arguments For and Against Special Programs/Units for Persons with Dementia

Arguments for	Arguments against
The needs of individuals with dementia are not the same. Trained staff in a special environment can produce measurable evidence of benefit in persons with dementia.	People need much the same care. Most nursing home residents suffer multiple illnesses, of which mental impairment is only one. They need regular nursing care.
Quality care should be available to all nursing home residents, but even in the best possible setting the needs of the cognitively impaired are different from those of the cognitively intact.	Provision of special units is unfair to other people who would also benefit from many of the environmental changes that help people with dementia. Instead of segregating people, the quality of all care should be upgraded.
Being around people whose mental functioning is higher can be stressful for persons with dementia, who must constantly struggle to process even simple information. This may be one cause of behaviour problems.	Placing persons with dementia with cognitively well persons helps the persons with dementia stay alert by providing role models. Isolation in all-dementia units may lead to greater deterioration.
Special units permit special interior design, fire safety equipment, trained staff, and marketing efforts to attract private pay clients. The demand for quality ensures that beds in good facilities will fill quickly.	Special units must hold a bed open until a person with dementia needs it. This is more expensive than quickly filling beds with the next available client.
Cognitively well elderly persons have made it clear in several informal surveys that they do not want to spend their lives with persons who act "crazy" or are disruptive. The lucid client is vulnerable to loss of privacy, loss of personal property, interrupted sleep, and fear of harm by the agitated person. Efforts to protect the lucid client may result in overmedication and restraints, which have negative effects on persons with dementia. There are ethical issues involved in using persons who are paying for their own care as supervisors of other patients.	In mixed units, cognitively well individuals can help "look after" the person with dementia, which allows lower staffing levels and gives the well client something to do.

Exhibit 5.1 Arguments For and Against Special Programs/Units for Persons with Dementia (Continued)

The current demand for specialized units is such that people will transport family members long distances for residential care.	In areas with a low population density, there will not be enough persons with dementia to support special units, particularly day care.
An all-dementia unit allows staff to develop expertise in care for clients. This benefits residents and is rewarding to staff. Experience has shown that staff do not necessarily "burn out."	Staff will quickly "burn out" on a dementia unit. The issue of burnout and staff satisfaction is not unique to dementia care, but reflects pervasive problems in long-term care.
Patients' rights laws, ombudsmen, and quality assurance regulations are to protect persons who are not competent. The new focus on dementia reduces the risk that individuals would be poorly served.	A program serving persons with dementia would create a ghetto in which no one would be able to report abuses or be a legally capable witness. Ombudsmen rarely serve board and care facilities. Persons with dementia often outlive the family members who advocate for them.
Dementia is a medical specialty long overdue for recognition. Specialty programs would attract physicians and nurses interested in this field.	Dementia is not a medical specialty, deserving of separate designation and specialization, because the needs of these individuals are primarily psychological and social.

Source: United States. Congress. Office of Technology Assessment. Task Force. Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and other Dementias. 1988. 244 The task force reviewed the following:

M. Ablowitz, "Pairing Rational and Demented Patients in Long-Term Care Facilities," Journal of the American Geriatrics Society 31:627-628, 1983; J. Bergman, "Mentally Ill in Nursing Homes? Yes, if....," Geriatric Nursing 3:98-100, 1983; R. Cook-Deegan and N. Mace, "Care of Patients With Dementia," Testimony, California Task Force on Alzheimer's Disease, 1986; D. Coons, "A Residential Care Unit for Persons with Dementia" contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986; G. Hall, V. Kirshling, and S. Todd, "Sheltered Freedom: The Creation of an Alzheimer's Unit in an Intermediate Care Facility," unpublished paper, 1985; Hebrew Home for the Aged at Riverdale, "Institutional Approaches to the Care of Individuals With Dementia," contract report prepared for the Office of Technology Assessment, U.S. Congress, 1986; N.L. Mace, "Home and Community Services for Alzheimer's Disease: A National Conference for Families," U.S. Department of Health and Human Services and Alzheimer's Disease and Related Disorders Association, May 2, 1985; J. Pynoos and C.A. Stacey, "Specialized Facilities for Senile Dementia Patients," The Dementias: Policy and Management M.L.M. Gilhooly, S. Zarit, and J.E. Birren (eds.) (Englewood Cliffs, NJ: Prentice Hall, 1986).

- to prevent excess disability due to other health problems or medication;
- to minimize use of psychoactive medications and physical restraints;
- to maximize an individual's ability to see and hear;
- to enhance remaining function rather than restore function lost through the disease progression;
- to reduce long hours of idleness;
- to enhance a participant's sense of appropriate roles (i.e. friend, parent, volunteer) that reinforce a sense of personhood and dignity;
- to create a home-like environment in which participants are dressed and well-groomed;
- to use flexible, creative and structured and unstructured approaches to activities;
- to emphasize the importance of respect for participants and individualized approaches;
- to recognize the importance of a benign, non-stressful, supportive environment; and
- to support the individual in a continuing relationship with the family.

The balance of this section discusses various types of dementia programs: respite programs, offering temporary relief from caregiving through adult day care and in-home or out-of-home programs; specialized programs or units in nursing homes; educational or family support groups; and other programs for dementia patients and caregivers. Cost information is provided if available in the source material. Problems and issues facing each type of program are also discussed.

5.1 Respite Programs

Respite care is limited-term, substitute care for dementia patients provided in the absence of the usual caregiver. Most respite care is provided informally by friends and family. It can be offered through formal programs in the patient's home, at an adult day care centre, in a foster home in the community, or in an institution such as a nursing home or hospital. The period of care may vary from a few hours to a full day or several days or weeks of overnight care. Programs vary in terms of level of care, services offered and staffing. The patient is the recipient of the service, but the primary beneficiary in most cases is the caregiver (Gwyther 1986).

Program evaluations suggest several common elements of successful respite programs (Gwyther 1986). They are offered through a long-term care agency that has a range of services; employees are trained through programs that are also open to family caregivers, to ensure uniformity of approach to patient care; the same respite caregivers are available regularly; and

the families are allowed to pay something for the service but subsidies are provided to ensure that families obtain enough respite to be of real assistance.

Four types of respite programs are discussed here, by way of example:

- in-home respite care
- foster home respite care
- institutional respite care
- adult day care.

5.1.1 In-home respite care

The literature search included articles on two in-home respite care programs, somewhat different from each other (Exhibit 5.2). The Greater Dodge Area Respite Services in Wisconsin offers up to three days of care in the patient's home. Initially, families were expected to request one or two days of care at a time but, in practice, they frequently requested only part of a day (Hildebrandt 1983). Most clients in the first year of the program sought respite because of a crisis; in the second year, program workers were encouraging caregivers to use respite care to strengthen themselves.

Regular use of respite care is a feature of a Portland, Oregon program that requires caregivers to accept a minimum of three hours of respite every two weeks, in keeping with the program's goal of preventing early or unsuitable institutional placement because of caregiver burnout (Dunn 1986). The respite caregiver assigned to the family provides care for as long as the family is in the program. Most families use the service for the five or six months preceding institutional placement of the patient, and program organizers see a need for earlier intervention, perhaps through increased marketing of the program. In some cases, in-home skilled care becomes needed and the less-skilled, respite care must be discontinued even though circumstances in the client's home are becoming increasingly difficult.

Respite caregivers in both programs receive training -- 6 to 60 hours in Wisconsin[1] and 18 hours in Portland. Caregivers in the Wisconsin program assume all the responsibilities of the regular full-time caregiver, working from a plan of care prepared by the family and program coordinator, a nurse practitioner. The respite caregiver keeps a log and may call on the

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1 Figures on training through the Greater Dodge program are not available. It is one of 11 programs in Wisconsin, which offer 6 to 60 hours of training.

coordinator for assistance. Caregivers in the Portland program function as companions, assisting with feeding, walking and toileting but not with homemaking, transportation or personal care services. Both programs include an initial home visit by the coordinator.

Exhibit 5.2 In-home Respite Programs

	Greater Dodge Area Respite Services, Wisconsin	Senior Respite Care Program, Portland, Oregon
Parent Organization	Not stated. The state funds program at the county level	Co-sponsored by ADRDA and a medical centre
Other Services Offered	Foster-home respite program	Referrals to other services
Hours of service	4 to 24 h/day for up to 3 days	Minimum of 3 h every 2 wks. Maximum of 16 h/week
Staff	Coordinator (nurse practitioner), trained respite workers	Full-time director, part-time clerk, trained respite workers
Fees	Sliding scale. $18-72 for 24 h; $1.50-3.50/h for less than 12 h (1983 rates)	Sliding scale. $2-5/h, billed monthly (1985)
Eligible Patients	Elderly dependents (82%), developmentally-disabled (13%), physically-disabled (5%)	Frail elderly, Alzheimer's disease (50%), plus dementia patients with stroke or Parkinson's disease
Hours of Care Provided	2614 h in first 12 months	7108 h of care for 86 families (1985)

The Portland program found families used the service four to six hours each week. Male caregivers and adult children scheduled longer respite periods, usually for a specific recreational purpose, than did the elderly wives, who were reluctant to use more than the minimum hours required by the program. (About 80 per cent of the caregivers were women, and most were wives.) Program administrators also found the respite program was often the first service used by the family, and therefore referrals were made during intake. Also, respite caregivers' training included orientation to available services, and monthly services bulletins were mailed to families.

The Portland program was started in 1983 by a medical centre with a $10,000 grant from the local Area Agency on Aging plus $56,000 from a private trust, administered by the local chapter of the Alzheimer's Disease and Related Disorders Association. The hospital provided office space and services such as telephone and personnel. The total budget for 1985 was not provided in Dunn (1986), although that year family fees totalled $31,723 or an average of $4.46 hourly for care, and covered respite caregivers' salaries, supplies, and some administrative salaries.

5.1.2 Foster-home respite care

Hildebrandt (1983) mentions that families needing more than 72 hours of care from the Wisconsin respite program were encouraged to use one of the respite foster care homes available through the program. Fees for foster home care ranged from $10 to $26 for 24 hours of care (1983 rates), and subsidies were available. In the first 12 months of operation, foster-home care accounted for about 12 per cent of the total hours of respite care provided by the program. Many families using the program needed respite for only a few hours, and some were reluctant to use out-of-home respite.

5.1.3 Institutional respite care

The literature search yielded descriptions of three institutional respite programs (Exhibit 5.3). A 5-bed unit in a nursing home in California accepts chronically-ill veterans after a home visit, review by a screening committee and a trial visit of three days and two nights (Ellis and Wilson 1983). Patients who benefit the most from the program initiate their visit and view it as a welcome change from their schedule. The least successful referrals are moderate and severe Alzheimer's disease patients who either become overly fearful in their regular caregiver's absence or wander away and cannot be successfully contained in an open unit.

Program administrators found clients needed more extensive care than anticipated, and one extra nurse and aid were required on the 50-bed unit containing the respite care beds. Patients were more demanding than anticipated, and a strong nursing leader was needed to work with patients and staff.

Two levels of respite care are available through a suburban New York City centre for nursing care, which offers residential care in an apartment for elderly dependents requiring only the services of a housekeeper companion, and institutional care for patients with advanced Alzheimer's disease, unsafe ambulation, or medical needs (Spence and Miller 1986; Miller, Gulle and McCue 1986). Started with the support of the local chapter of the Alzheimer's Disease

and Related Disorders Association, the program provided 16 respite visits in the apartment (located adjacent to the nursing facility) and six in the institution during the first year. During the respite visit, patients in the apartment are encouraged to participate in nursing facility programs, and staff (dieticians, social workers, personnel, administration) can be shared between the respite program and nursing facility.

Most caregivers used the program for vacations or general relief, although three needed respite for a crisis and one used the visit as a trial for nursing home placement. Four of the 18 caregivers rated the respite visit as unsatisfactory, a rating the researchers said was due to the inability of the family caregiver to relinquish responsibility and control (Miller, Gulle and McCue 1986).

Exhibit 5.3 Institutional Respite Care Programs

	Veterans Administration Medical Center, California	Nathan Miller Center for Nursing Care, Inc. New York	University Hospital, Saskatoon
Parent Organization	Nursing home care unit	Centre for nursing care	Hospital
Other Services Offered	Nursing home	Nursing home	Day hospital, geriatric assessment unit
Facility	5 beds in 150-bed nursing home	2-B. apt. plus beds in nursing facility	Space as available in 18-bed geriatric assessment unit
Eligible Patients	Chronically-ill veterans, cared for at home, not needing hospital care	Frail elderly plus Alzheimer's disease	Impaired elderly (55% intellectual impairment; 20% physical; 25% both) living at home
Fees	Not stated	$60/day apt. $120/day facility (1986)	Not stated
Duration of Visit	Average of one week	Average of 12 days; range of 3 to 70	Intermittent (3 days every 3 to 4 weeks); holiday (2 weeks/ yr.); and as needed during caregiver illness
No. of Patients	Serves 126 families in program's fourth year	18 patients in first year, for 22 respite visits	During 3 years, 28 patients received 127 admissions

Saskatoon's University Hospital offers day hospital attendance of one to five days each week plus respite admissions as part of a planned program of aftercare following in-patient assessment (Dunn, MacBeath and Robertson 1983). Three types of hospital respite care are offered:

- planned intermittent respite every three to four weeks, usually over a weekend, to prevent caregiver burnout or to help keep the patient at home while waiting for a long-term care placement;
- holiday respite of up to two weeks, once each year; and
- respite to allow caregivers to overcome an illness or undergo elective surgery.

Most admissions (89 per cent) were for planned intermittent respite. Patients use the program for an average of 10.8 months, in a range of two months to 28 months. Almost all the patients attended the day hospital. At the outset of the three years studied by the researchers, all patients lived in their own or a child's home; at the end, 36 per cent remained at home, 50 per cent were in a long-term care facility, and 14 per cent had died. The researchers concluded that the respite care program had enabled the patients to remain at home longer than would have been possible otherwise.

The researchers also found 46 per cent of the families received no home care services of any kind, suggesting that the delivery of in-home services needs to be revised to help more people in need of them.

5.1.4 A mixed program of respite care

A program affording access to five respite care services provided by several organizations is described by Perdue (1984). Tapping state funds for the Respite Demonstration Project, the Metropolitan Commission on Aging (MCOA) in Syracuse, N.Y., obtained funds for administration plus $120,000 to help clients pay for respite services. The MCOA then contracted the Home Aides of Central New York, Inc. (HACNY), a voluntary non-profit home health care agency, to develop and co-ordinate the program. The two organizations had worked together since 1980, offering respite care in the home for up to four hours weekly. With access to the demonstration project funds in 1982, the organizations were able to develop a program providing more than 24 continuous hours of respite. The two requirements for eligibility are residence in the county and establishment of a caregiving and care-receiving relationship between two or more people. Priority is given to frail or disabled adults 60 years of age or older.

Care options available through the program are as follows:

- Companion-homemaker respite care. Respite caregivers employed and trained by HACNY in personal care, emergency procedures, psychology of aging and home management provide care to clients whose medical condition is fairly stable and who are somewhat self-sufficient. The emphasis is on providing companionship in the usual caregiver's absence.
- Homemaker-home health aide respite care. Again, respite caregivers are employed and trained by HACNY, receiving 125 hours of state-approved training. They provide extensive personal care and some nursing.
- Adult home respite care. One adult home in the community accepts respite clients who are fairly independent and medically stable. The home provides basic supervision, meals and activities, but not nursing care.
- Health-related facility respite care. Limited nursing care and supervision are provided to individuals who are somewhat independent but need some nursing care. Assessment of patients requiring this type of respite can be difficult.
- Skilled nursing facility respite care. Three facilities accept respite patients as space becomes available. They provide extensive nursing care and 24-hour supervision, as would be required by a paralysed stroke patient or a patient with Alzheimer's disease requiring 24-hour supervision.

Patients are admitted to the program through a home evaluation used to gather general information about the patient plus financial information on ability to pay. (State funds are used to subsidize up to 100 per cent of costs.) The program coordinator and public health nurse who conduct the evaluation also administer a medical assessment test used throughout New York State to determine what level of institutional care a person requires. Test scores determine what level of out-of-home respite can be offered and guide decisions on levels of in-home care. In most cases, the respite option requested by the client is provided.

Exhibits 5.4 and 5.5 show hours of service for each type of care provided through the program and the costs entailed. Companion-homemaker care was the most frequently-requested option, closely followed by skilled nursing facility. The average length of respite care was about twice as long in the skilled nursing facility than in the in-home option, and daily costs were about 60 per cent higher.

Exhibit 5.4 **Caseload Statistics according to Option of Care (n = 212) within the Respite Demonstration Project, New York**

Level of Respite Care	No. of Cases	Hours of Services	Cost of Service	Client Contribution	Cost Charged to State Funds
Companion-homemaker	93	13,556	$34,293.13	$8,247.50	$26,108.58
Homemaker-home health aide	20	2,821	14,902.67	2,692.74	11,519.52
Adult home	1	336	392.00	200.00	192.00
Health-related facility	7	2,328	5,460.00	460.00	3,180.00
Skilled nursing facility	91	26,694	112,806.64	17,472.50	81,145.50

Source: Perdue (1984, 35)
Note: Data appear to include all admissions from November 1982 to April 1984.

Exhibit 5.5 **Average Cost and Length of Stay per Respite Option (n = 212) within the Respite Demonstration Project, New York**

Level of Respite Care	Average Cost Per Day	Average Length of Respite Care	Average Cost Per Case
Companion-homemaker	$60	6.0 days	$368.74
Homemaker-home health aide	105	4.0	745.13
Adult home	28	14.0	392.00
Health-related facility	70	14.3	780.00
Skilled nursing facility	100	12.5	1,239.63

Source: Perdue (1984, 36)
Note: Data appear to include all admissions from November 1982 to April 1984.

5.1.5 Adult day care programs

The first day care centre for seniors in the United States opened in 1957. In 1974, there were fewer than 15 centres, but about 10 years later there were more than 900 (Kerwin 1985). Increasingly, day care is an important component of care in other countries. The day hospital has become the focal point of many geriatric services in the UK, including medical assessment and treatment, rehabilitation, and socialization. Since the early 1970s, all new nursing homes in Denmark have been required to have a day nursing home offering community residents the same services available to home residents. Although the day service is used primarily by the physically-disabled, in some facilities at least half the clients have an organic brain disease (Nusberg 1988).

The National Institute on Adult Daycare in the United States defines adult day care as "... a community based program designed to meet the needs of functionally impaired adults through an individual plan of care" (National Institute on Adult Daycare 1984, 20). Health, social and related support services are provided in a protective setting for any part of the day, but for less than 24 hours. The goals of adult day care are to:

- promote independence;
- maintain the individual's present level of functioning as long as possible, preventing or delaying deterioration;
- restore and rehabilitate the individual to his/her highest possible level of functioning;
- provide support, respite and education for families and other caregivers;
- foster socialization and peer interaction; and
- serve as an integral part of the community service network and the long-term care continuum (National Institute on Adult Daycare 1984, 22).

Day care programs serving dementia patients were described in a survey of 346 adult day care centres plus articles on six individual programs. While the individual programs described in the literature primarily served dementia patients, the survey included day care centres that integrated dementia patients with persons with no cognitive impairment. Day care centres for cognitively or physically impaired persons can also be integrated with senior citizens' centres; one such program was also described in the literature (Kerwin 1986).

o Survey of adult day care centres

Working from mailing lists of the National Institute on Adult Daycare and the Alzheimer's Disease and Related Disorders Association, Mace (1984a, b) sent questionnaires to 444 centres serving dementia patients in 1983; 346 returned completed questionnaires (Mace 1984a, b).

Almost half the centres reported that fewer than 25 per cent of their clients are dementia patients, as shown below:

Percentage of Clients with Dementia	No. of Centres	Percentage of Centres Reporting
75-100	17	5
50- 75	64	19
25- 50	100	29
Less than 25	161	47
Not reporting	4	—
	342	100

Source: Mace (1984b, 39)

Although most centres limited the number of clients with serious cognitive impairments, the survey indicated that staff worked hard at keeping cognitively impaired patients in the program, usually by spending more time with the patient to control problem behaviour. More than half of the centres accepted dementia patients who were incontinent, became very agitated, or wandered. Most centres indicated they accepted dementia patients because of the families' need for respite; 87 per cent offered family counselling and 83 per cent encouraged families to join support groups. Of the centres offering discussion groups for families, half reported poor attendance and some suggested families did not have enough time to attend meetings.

Centres rarely had a physician on staff. Staff usually comprised nurses, social workers, rehabilitation therapists and para-professionals. Nursing, social work care and rehabilitation therapy were offered more frequently than medical, neurologic or psychiatric care.

There were no significant differences in the services offered by centres specializing in dementia patients and centres with only a few dementia patients. However, the specializing

centres required one staff person for every three or four patients, compared with a ratio of 1:8 suggested by the National Institute on Adult Daycare (Kerwin 1985).

The centres were asked to indicate the most frequent activities at the centre and the activities that were the most successful with dementia patients. Of the 10 activities offered most frequently by all the centres, only three (physical exercise, reality orientation and walks) were among those rated by the centres as most successful with dementia patients. Activities that were most successful with dementia patients were (in rank order): sing alongs, physical exercise, walks, reminiscence groups, visits from children, active games, outings, listening to music, reality orientation and visits from pets. Activities were usually offered to the cognitively well and dementia patients in mixed groups, although activities requiring effective cognition and reading skills (i.e., word games, newspaper reading, discussions) were offered only to the cognitively well. Fifty-seven per cent of the centres reported no problems mixing dementia patients with others in the centre, while 43 per cent said the cognitively well had trouble mixing with or accepting the dementia patients.

o Day care centres for dementia patients

The literature search yielded descriptions of six day care centres primarily serving dementia patients. Most of these centres pursued the general goals of providing caregiver respite and providing a meaningful experience for patients, although precise statements of goals varied. Atlanta's Community Services Program, for example, set the following goals (French 1986, 20):

- to support and enhance the home and community as the setting of choice for care of the family member with Alzheimer's disease in the early and middle stages;
- to relieve families of their caregiving burden periodically;
- to help persons with Alzheimer's disease function at maximum capability in a structured and caring environment;
- to provide affordable care; and
- to use the program as a setting for staff training.

Similarly, the Harbor Area Adult Care Center in California has as its goal "... to support the family by providing respite for the caregivers and by creating a meaningful situation outside the home for the person who is impaired" (Sands and Suzuki 1983, 21). The New York Institute for Aging's Saturday program was designed to provide a variety of stimulating activities for participants and to offer weekend respite to caregivers (Rabinowitz 1986).

All centres offered meals, social and recreational activities and indoor and outdoor exercise; activities were geared towards the patients' capabilities and feeling of self-esteem, and often

had a therapeutic or rehabilitative component. For example, patients in several programs help prepare lunch, thereby enhancing self-esteem and social relationships plus reinforcing practical skills. The need for a daily routine and adequate space for all patients was also mentioned (French 1986; Sands and Suzuki 1983).

All the centres offered counselling or a family support group, either through the centre or a parent organization (Exhibit 5.6). While the two California centres appear to be independent of other organizations, the Atlanta program is sponsored by the local chapter of the Alzheimer's Disease and Related Disorders Association (ADRDA). The San Diego program was developed by ADRDA but was incorporated as a separate entity so that the local chapter would be spared legal, fiscal and supervisory responsibilities (Sanborn 1986). It also has a working relationship with a geriatric assessment clinic and the Institute for Research on Aging at the University of California. The other three programs included in Exhibit 5.6 are offered by a geriatric or rehabilitation centre. The parent organization offers various services allied with the day care program, such as family support groups or other types of respite care, either directly by the parent organization or indirectly through referrals to another agency. Intake procedures varied, but usually entailed assessments by two or more professionals: nurses, social workers, recreation therapists and physicians.

The ratio of staff to patients ranges from 1:3 to 1:5. Daily attendance ranges from 12 to 26. Centres were supported by fees, charitable contributions, and other funding sources. Expenditures on administration and other costs were not reported in the literature.

Descriptions of each centre highlighted its unique aspects or primary focus. The Atlanta Community Services Program developed by ADRDA was viewed as the beginning of a continuum of care that includes in-home respite care, day care and family counselling (French 1986). As part of the intake assessment, for example, the coordinator begins a family counselling process which includes emotional support, information, referral to ADRDA services, and advice on patient care after the patient leaves the program. Day care is offered a minimum of two days and a maximum of five days each week. In its first year (1985), the centre served 71 persons, including 47 who had left by the year's end; in most cases, families could not continue home care and their patient was placed in an institution.

The 1985 budget of $130,027 was supported by community contributions (service clubs, charitable foundations) of 66 per cent of the total, ADRDA (16 per cent), fees (13 per cent) and government funding (5 per cent). A state grant of $118,500 supported a second centre scheduled to open in 1985.

The Harbor Area Adult Day Care Center in California emphasizes strategies to maximize patients' independence. Three small groups meet daily to work on patients' particular needs. One group for patients with profound language deficits stresses non-verbal activity; another group for disoriented and confused patients uses reality orientation techniques; a third group for patients with minimal cognitive deficits employs remotivation techniques. The 1981 budget of $65,000 was supported by patient fees (47 per cent) and various individual and foundation donations. A total of 2,785 days of service was provided to 58 families at a cost of $23.35 per client day (Sands and Suzuki 1983).

Exhibit 5.6 Day Care Programs for Dementia Patients

	Atlanta Community Services Program, Georgia	Harbor Area Adult Care Center, California	San Diego Alzheimer's Family Center, California
Parent Organization	ADRDA	Independent organization	Independent organization
Other Services Offered	In-home respite, family counselling, plus other ADRDA services i.e., support groups	Individual counselling, referrals, social events	Evaluation of family needs, support group, social events, in-home respite counselling
Clientele	Patients with Alzheimer's disease or related disorder	Primarily cognitively impaired; some physically impaired	Moderate to severe dementia
Fees	$5-26.50/day (1985) based on ability to pay	$16/day (1981)	Not available
Capacity	15 spaces serve 20-25 patients	35 spaces; 17-26 daily attendance	25 spaces; 22-25 attendance
Staff	2 coordinators (shared with in-home respite), manager and two assistants, Admin. services through ADRDA, volunteers	5 full-time, 3 part-time, 10 h/day volunteers. Ratio of 1:5 staff to patients preferred	No details. Registered nurse supervises
Facility	Church with garden	Former school. 4500 sq.ft. outdoors, 4500 sq.ft. indoor	Wheelchair-accessible house
Program (in addition to Meals, Social and Recreational Activities)		Small groups for special needs, i.e., reality orientation for confused patients	

Exhibit 5.6 Day Care Programs for Dementia Patients (Continued)

	New York Institute for Aging, New York	Wisconsin Regional Geriatric Center	Burke Rehabilitation Center, Cornell University
Parent Organization	Private institute	Geriatric centre	Rehab centre
Other Services Offered	Diagnostic evaluation, psychologic testing, drug treatment, support group, legal and financial counselling	Support group	Diagnostic evaluation, seniors' day care, family support group
Clientele	Memory and cognitive impairment	Alzheimer's disease	Dementia patients
Fees	$50/day (1986)	Up to $25/day (1983)	Up to $70/day (1984)
Capacity	12; Saturday only	12; 2.5 days/wk	13 attend daily; 28 enrolled; 4 days/wk
Staff	1:3 staff-patient ratio, occupational therapist, 2 students	Recreational therapist, geriatric nurse, aide	1:3 professional staff-patient ratio - Access to centre specialists, interns, volunteers
Facility	Basement office space in townhouse	Geriatric centre	Rehabilitation centre
Program		Nursing care, including monitoring for medical problems	

The Alzheimer's Family Center in San Diego was established as a program for people in the later stages of dementia, since no programs were available for people with severe incontinence, eating and swallowing disorders, combativeness or other problem behaviours (Sanborn 1986). The centre offers three types of care: five days each week, to enable caregivers to work; intermittently scheduled respite care; and care on an emergency or unscheduled, intermittent basis. The centre was established in a house, in order to create a home-like atmosphere appealing to both caregivers and patients.

Non-verbal communication is emphasized and staff are trained to be sensitive to non-verbal cues. Although the program focuses on persons with advanced dementia, early stage patients are invited to join intermittently as volunteers performing useful tasks at the centre. This approach helps patients cover any embarrassment about their participation in the program and most feel needed and secure. Such an early introduction also helps the patient adjust to the centre later.

Budget information was not available, although the funding mechanisms apparently required that fees for service cover more than 50 per cent of operating costs.

The centre operated by the New York Institute for Aging is open only on Saturday from 10 a.m. to 3 p.m. because many caregivers are without their usual help on weekends and other centres are closed then. The program cannot accept incontinent patients or patients in wheelchairs because its basement location is inaccessible and has a bathroom that is too small to allow staff to change patients' diapers (Rabinowitz 1986).

The Alzheimer's Disease Day Treatment Program at the Wisconsin Regional Geriatric Center emphasizes therapeutic recreation for patients and a support group for families (Keyes and Szpak 1983). The support group meets weekly while patients attend a three-hour day care session, offered in addition to two full days of day care each week. The centre also emphasizes health maintenance through such activities as personal care exercises to reinforce good hygiene habits and careful inspections for medical problems. The program costs about $35 daily for each of the 12 patients (1983), with fees charged on a sliding scale of up to $25 daily.

The day care program at the Burke Rehabilitation Center, Cornell University (also referred to in the source material as a day hospital program) was started as an expansion of the Senior Day Gare program at the centre. Intake begins with a complete diagnostic evaluation; patients qualified for the program must be ambulatory, have no systemic illness, and retain some capacity for social interaction. Over four years, the centre accepted 69 patients who stayed an average 12.6 months. Families favorably evaluated the centre and the accompanying support group but said the cost of the program ($70 daily in 1984, subsidies available) and lack of transportation to it were problems. Many requested longer hours, increasing to 8:30 a.m. to 5:30 p.m. from 9:15 a.m. to 3:30 p.m. (Panella et al. 1984).

Clubs for dementia patients in Jerusalem, Israel, provide a somewhat different model of day care (Rosin et al. 1985). Four clubs with up to 15 members each meet in various community centres for three or four mornings every week. The program includes reality orientation,

socializing, handcrafts, art therapy, music and movement, dance therapy and physiotherapy, and is conducted by a social worker or a community worker plus an assistant.

The clubs were initiated by a geriatric unit of a medical centre after staff became concerned about the lack of community resources for caregivers and patients after discharge from the medical centre. The program was intended to provide social stimulation appropriate for dementia patients plus respite for caregivers. Referrals to the clubs are subject to a home visit by the social worker and subsequent screening by a committee with regard to suitability for membership; patients with a dominant psychotic illness rather than cognitive defect are ineligible for membership, for example, as are severely incontinent patients.

The clubs have organized transportation for members to maximize the caregivers' period of respite. Caregivers' support groups meet every two or three weeks for general discussions, social events and guest speakers. Training sessions provided periodically to group leaders, drivers, and volunteers have been joined by others in the community who work with the elderly.

o Day care centre integrated with a senior citizens' centre

Kerwin (1986) describes a demonstration project in Delaware to integrate an adult day care program with an established seniors' centre. At the outset, program planners were concerned about whether the centre members would accept the day care participants and their claims to the centre's scarce resources. Also, would members view the change in the centre as yet another instance of loss of control over their environment?

A receptive environment for the day care program was created by discussions with members at four open meetings before the program started. A members' committee reviewed program plans, and two active supporters spoke informally to others. Two months into the program, the centre director discussed staff evaluations of the program with centre members and solicited their comments. There appeared to be general agreement about the success of the program, with participants forming supportive relationships through shared meals and recreation. Integration also allowed for a reduction of program costs and the sharing of professional staff. It accommodated the needs of seniors' centre members who were becoming more dependent and needing more individual attention, plus the needs of caregivers who attended the centre with their ailing spouses. Cicirelli (1986) also notes that integration provides the cognitively-well participants with an opportunity to help others and thereby gain self-esteem.

5.1.6 Key issues and problems in respite care

The caregiver may be the largest initial barrier to use of formal respite services. Caregivers may be uncertain of the respite caregiver's ability to care for their patient, or they may feel guilty for relinquishing responsibility, even temporarily. These caregivers need support to use respite services, such as a recommendation from the family doctor or other "permission" to seek relief. After years of caregiving, some may be so socially isolated that they have no leisure outlets, or they may need transportation or other supports to use their leisure. Also, caregivers may be reluctant to alter a working routine for as little as four hours of respite, which upsets the patient and leads to subsequent difficulties in patient management (Gwyther 1986; Hildebrandt 1983: Dunn 1986; Ellis and Wilson 1983; Mace 1984a).

In the United States, the dichotomy in funding of health and social services has been a problem in developing respite services. By the time they seek help, most families need a combination of nursing care and companionship, funded from different sources (Gwyther 1986).

Other findings for respite services of all types are that (Gwyther 1986):

- Effective outreach to potential users is difficult and once they become interested in a service, the red tape surrounding it may deter them from using it.
- Services must be offered in appropriate combinations if they are to work. For example, a day care program may need a transportation and escort service.
- Services must be geared towards early intervention, to avoid breakdown in the family's ability to provide care.

Gwyther (1986) notes that many professionals believe the potential for respite programs could be enhanced by targeting services to patients earlier in the course of the disease and marketing it to families as a treatment strategy rather than as custodial care. "This highlights the specific value of day care programs over in-home respite" (Gwyther 1986, 6).

In addition, various authors noted problems or issues with reference to a specific respite program. Some problems are particularly relevant to that type of respite while others underscore shared problems.

o Issues in in-home respite care

- Caregivers were concerned that patients would not accept the respite caregiver and that the respite caregiver would not tolerate the patient's behaviour (Hildebrandt 1983).

- Respite caregivers may become too involved with family matters and routines and may become frustrated by their inability to help a deteriorating patient (Dunn 1986).
- It is difficult to reach families when the program can still make a difference to their ability to provide care. Requests for help are usually made when the caregiver is near collapse and approaches an agency that provides a referral (Dunn 1986).
- Support groups and presentations to community groups were particularly effective marketing tools; paid media advertisements were not effective (Dunn 1986).
- Payment posed various problems. The sliding scale seemed like welfare to some, while others had difficulty paying the minimum (Dunn 1986).

o Issues in institutional respite care

- Two views on initial patient assessments were found. Ellis and Wilson (1983) believed a home visit would help the California nursing home anticipate the level of care required, patients' behavioural problems, caregivers' guilt and patients' resistance to the program. In contrast, Spence and Miller (1986) found that an evaluation at the facility in New York allowed for a better assessment of the patients' reaction to the facility. Also, home visits were too expensive for the program to support.
- Institution staff have difficulty accepting that respite care is primarily for caregiver relief, not patient rehabilitation (Miller, Gulle and McCue 1986).
- Brief stays are problematic. The high cost of nursing home admission procedures makes admissions of less than two weeks too costly (Gwyther 1986; Miller, Gulle and McCue 1986). Also, patients have difficulty adjusting to a new environment in less than three weeks. Caregivers who do not realize or accept the patient's difficulty may view the whole respite experience negatively (Spence and Miller 1986). Finally, respite caregivers have difficulty familiarizing themselves with the patient's needs in a short period (Miller, Gulle and McCue 1986).
- Ideally, a number of beds in the facility should be dedicated to respite care, rather than placing respite patients in beds as they become available. This approach would help in planning for admissions and overcome problems of shortages but would be more expensive because beds would be empty until the program was established (Miller, Gulle and McCue 1986; Gwyther 1986).
- Effective marketing strategies are difficult. The New York nursing centre found that newspaper advertisements were ineffective, and a part-time community affairs consultant was hired for outreach, in addition to letters to agencies and clergy introducing the service (Miller, Gulle and McCue 1986).
- Mental illness may be difficult to detect during an intake interview and may make a patient unsuitable for the respite program (Spence and Miller 1986).

- Although the New York nursing centre's program lost money, it generated community goodwill and interest in long-term placements and identified the centre's programs as possible recipients of requests and gifts (Spence and Miller 1986).

o Issues in adult day care centres

- In general, staff at day care centres are not trained in the special needs of Alzheimer's patients (Gwyther 1986).
- Family caregivers find the availability and acceptability of day care limited by difficulties with transportation and escorts, and inflexible hours (Gwyther 1986). Some centres reviewed in the literature offered hours accommodating a caregiver's employment schedule, while others were open for a shorter period.
- The patient's reluctance to try new activities also discourages families from using day care. Families delay introducing day care to the patient at an early stage, when adaptation would be easiest, and then must face several weeks of the patient's resistance (Sanborn 1986; Gwyther 1986).
- In the United States, some funding sources require that centres provide rehabilitation for patients, although most centres do not require patients to have rehabilitation potential in order to be admitted. This discrepancy between the goals of funding programs and the reality of the centres' operations may be stressful for centre staff and may also limit a centre's willingness to accept dementia patients (Mace 1984b).
- Centres experience a variety of problems with patients' families. Some families are unable to accept the client's impairments or complain about lack of improvement. Some families linger too long at the centre while others are unwilling to cooperate, by failing to provide adequate information on the patient, to participate when requested, to take the patient to the doctor when requested and to pick up the patient when called because the patient is ill (Mace 1984b).
- Mixing demented and cognitively-well persons in centres raises several unresolved issues. Issues include the needs and rights of the cognitively well; staff training in the needs of dementia patients; possible benefits to dementia patients of associating with the cognitively well; and appropriate ratios of staff to patients (Mace 1984b).
- Some patients and their families cannot adjust to day care, despite staff efforts to ease the adjustment period. The survey of day care centres found almost half had discharged a patient in the previous six months because of an inability to adjust (Mace 1984b).

5.2 Specialized Programs and Units in Nursing Homes

Specialized units for dementia patients is a controversial and rapidly-growing development, according to the task force of the Office of Technology Assessment. Growth has been fuelled by the belief that special units foster better care and that cognitively-well residents prefer separate accommodation. Within the nursing home industry, some people believe special units are a good marketing strategy and that dementia patients are easier to care for together in a special setting.

Specialized units differ considerably in terms of the special features provided. Differences may be found in staffing and staff training, services offered, admission procedures, size, and architectural design. Although there is agreement that the physical environment affects residents' behaviour, there is no consensus on the best environmental features.

Most units reviewed by the task force served the same kind of patient: persons in the middle stage of the illness, who exhibit problem behaviours and who are ambulatory, capable of some self-care and able to participate in activities. Most nursing home units transfer patients from the specialized unit to a regular skilled nursing unit when their illness progresses and they require a different kind of care. Some nursing homes have established "step-down" units to care for persons with more advanced cognitive impairment; these units offer special sensory stimulation, passive exercise and other activities intended to keep the patient as alert as possible (OTA 1988).

The balance of this section provides examples of special programs and units in nursing homes.

o Wesley Hall, Michigan

Wesley Hall, a residential treatment unit for elderly persons with Alzheimer's disease and related dementias, opened in 1983 as a demonstration project by the Institute of Gerontology at the University of Michigan (Coons and Weaverdyck 1986). Wesley Hall emphasizes social and physical milieu interventions to maximize residents' capacities and minimize deficits. Medical diagnosis alone is rejected as a basis for determining treatment, in favour of individualized programs based on observation and neuropsychological testing intended to reveal an individual's potential and limitations.

Wesley Hall occupies the top (fourth) floor of a retirement home located in a very old building. A small kitchen, combined living and dining areas and a den were decorated in a

home-like manner. Signs were posted to direct residents to various areas, to recognize residents' contributions and to help maintain personal identification.

Wesley Hall accommodates 11 residents and has a daytime staff-to-resident ratio of 1 to 4 (OTA 1988). Staff were trained by the Institute of Gerontology and weekly staff meetings are held to discuss difficult situations. The Institute has also developed a compendium of approaches, such as gentle cajoling, diversion and humour, that staff may use in everyday interactions with residents.

Programming on Wesley Hall includes the activities described below.

- Self-care. Staff try to do nothing for residents that they can do for themselves. Activities such as brushing teeth, bathing or getting dressed may be broken down into individual steps, with the residents doing those within their capability.

- Housekeeping chores. Although meals are brought from a central kitchen, residents prepare a variety of snacks and wash and dry their own dishes. They also help with other tasks such as setting the table, vacuuming, changing beds and folding towels. Residents eat their noon and evening meal together, but have breakfast in the dining room whenever they want it.

- Volunteer activities. Most residents have been able to participate in carefully-selected service activities, such as folding newsletters for the American Red Cross or preparing garnishes for the downstairs dining room.

- Activities with families and children. These include family potlucks every three or four months and shared activities with visiting children.

- Reminiscing. Small group discussion may focus on individual posters about events in a person's life, photograph albums, or antique objects such as button-hooks or a washboard that can be handled by everyone.

- Reading group. Residents who can still read, read aloud to others.

- Handcrafts. Occasionally, residents undertake a craft that can be divided into a series of steps, with each resident only doing those steps within his or her capability.

- Humorous activities. Clowning in make-up and costumes was discovered during a Hallowe'en party and has since entertained residents and visiting children. The activity must be introduced carefully, with no disrespect for participants. Other humorous activities, such as playing with one resident's hat collection, underscores the therapeutic value of humour.

- Spontaneous activities. Exercise, singing and games may be introduced spontaneously to relieve anxiety and tension.

Problem behaviours have been approached in various ways. During the first three months of the project, the night was almost as active as the day; staff responded by engaging residents in a variety of activities such as setting the breakfast table or baking cookies. By the fifth month, most residents were sleeping through the night, now that they were at home in their environment and tired from a full day of activities. The hours after the evening meal continued to be difficult, however, and staff therefore scheduled various group activities and provided reassurance and comfort at bedtime.

Incontinence was treated in several ways. All residents were examined shortly after admission and any infections contributing to incontinence were treated. Individual toilet schedules were developed for incontinent patients, and bathrooms were well marked. Liquid intake was increased to provide necessary fluids and to fill the bladder sufficiently to give a clear signal of the need to urinate. Staff learned to recognize various individuals' signals of their need to urinate, and directed residents to the toilet.

o Special nursing home unit for residents with Alzheimer's disease

Peppard (1986) describes a special unit developed over three years in a nursing home and subsequently adapted for use in several other homes. A community advisory panel of professionals (i.e. the clinical director of a veterans' hospital, a hospital discharge planner/RN), paraprofessionals (i.e. activity director, housekeeper), and nursing home administrators was assembled to guide program development.

A 10-bed unit was selected as the appropriate size and decorated to reduce over-stimulation or under-stimulation. Large print wall coverings were removed, for example, in favour of contrasting pastels. Residents selected an individual symbol, such as a leaf or a crescent, to mark their belongings. Each room has two or three beds, since private rooms were thought to increase isolation. A bio-board of photographs and biographical material was posted outside each resident's door.

In order to safeguard against inappropriate admissions, admission criteria included a complete neurological assessment. Residents in the middle to late stages of the disease are thought most suitable for the program. A discharge plan is prepared against the time when the resident enters the final stage of the illness, is no longer cognitively suited to special programming, and death is imminent. Individual care plans are prepared and reviewed weekly.

Each resident is assessed by the activity and social service directors and is assigned to a group of up to six others with similar abilities. The time between meals and after dinner is divided into 20-minute to 30-minute sessions that alternate between cognitive and physical activity. Not all patients participate in all activities, but are encouraged to engage in at least three or four. Activities of daily living are conducted at specific times each day, and incontinent residents are toileted every two hours and are kept on a strict hydration program.

Training and staff support appear to have contributed to high quality patient care; development of effective behaviour management techniques; and increased job satisfaction among staff, particularly aides, leading to low staff turnover. Training for professionals and paraprofessionals includes stress reduction techniques, death and dying issues, the aging process and indepth dementia training.

o A special care unit in a home for the aged

Southall (n.d.) describes a special care unit for 26 dementia patients in St. Joseph's Villa in Dundas, Ontario. Initially, staff planned to assess each resident before transfer to the unit and at three-month intervals thereafter. However, work load increases caused by construction of the new unit left staff with insufficient time for this assessment schedule. Rather, periodic assessment and individual care plans were prepared by the special care team, comprising the medical director, head nurse, the senior R.N.A. of the unit, the recreationist, the adjuvant (aide), and the coordinator of special care, a social worker.

Given the level of illness and functional ability among the special care patients, special care staff time was fully occupied with personal care, medication and meals. Any additional activities required the services of the recreationist, adjuvants, volunteers and others. These activities, held on a weekly basis, appeared to be more beneficial than stressful for residents: residents seem to remember visitors from one week to the next; many associate visitors with certain activities; and alertness and morale seems elevated for some time afterwards. Also, the sessions allow the recreationist to assess residents' levels of functioning each week and advise the special care team of any change.

The team is not entirely certain of the value of larger special events, such as outdoor picnics, visits from children or family parties, but do not wish to cancel them. Residents do not seem to become more agitated or distressed, and some express enjoyment.

Creation of a heavy care unit appears to be the next step in developing the home's program. As special care residents reach a level of awareness such that they can only respond to personal care and nursing, interaction among residents ceases to be therapeutic, the work load of staff increases, and plans must be made to discharge residents from the unit.

After several years of experience with the unit, the special care team has concluded that special care in a long-term care institution should be extended to all residents. The team found that many residents needed the program and would benefit from it, but did not qualify for it because they were not demented. Special care would best be provided to groups of residents as determined by their specific needs and levels of function.

o The Sensory Awareness Training Project, Jewish Home for the Aged, San Francisco

The project was designed to respond to the needs of cognitively-impaired residents with significant hearing and/or vision losses who appeared unable to benefit from available group programs (Maloney and Daily 1986). Since one-to-one programs were too costly, a group program was devised with the overall objective of providing sensory stimulation activities in order to maximize use of participants' remaining sensory channels, prevent sensory deprivation, and promote the maximum functioning of participants' communication, cognitive, social and self care skills.

Two groups of six were formed; the maintenance group comprised individuals at least partially oriented to time/place/person and who had varying degrees of sensory and motor loss. The intervention group comprised residents who needed maximum nursing care; they were disoriented and had significant physical limitations. The goal of this group was to increase social behaviour such as smiling, conversing and participating in self care, while the goal of the less impaired maintenance group was to prevent or slow the decline of skills.

The two groups of six residents met three times each week. Groups were usually conducted by the project director, a gerontic occupational therapist, and up to two student assistants. The length of the meeting and time spent on each activity varied according to the responsiveness of participants, with meetings usually lasting a half hour to an hour.

After initial greetings and introductions, participants handled sensory stimulation objects and participated in other activities designed to stimulate each sensory channel. Olfaction was stimulated first because of its neural connection to the reticular activating system, thought to be the centre of arousal. The next activity included tactile, visual and vestibular components; a taste activity preceded the closing portion of the meeting. Activities were organized around a theme; a theme of summer vacation, for example, could include presentation of a strong-smelling piece of seaweed, a colour photograph of sunbathers, a bucket of sand with various objects lost within it, and glasses of ice and water.

Assessment of participants and clinical observations showed that 10 of the 16 participants maintained or improved cognitive function during their involvement in the project. Maloney and Daily (1986) commented that without use of controls, the factors contributing to the participants' performance could not be identified. Possibilities include the staff approach, the sensory stimulation activities, the group atmosphere of acceptance and sense of community, and the opportunity to express feelings and interact with peers.

o Social work groups with persons with Alzheimer's disease

Carey and Hansen (1986) describe two group programs for residents of the Alzheimer's unit at the Dallas Home for Jewish Aged, and some of the lessons learned through the programs.

A ten-session newcomer's group met weekly for 30 to 45 minutes to help newly-admitted residents adjust to the home. Attendance ranged between four and nine. Each session began with introductions and the first half of the meeting usually involved greetings and residents' anecdotes about significant events during the previous week. In the second half, the leader initiated conversation around a non-threatening theme, such as hobbies, birthplaces or careers.

Group skills of participants appeared to improve while the sessions were in progress, but were not carried into the larger environment of the home. Once participants left the meeting room, behaviours such as bickering resumed. Participants did adjust to the home, but what role, if any, that the newcomers' group played was difficult to assess.

A current events group met weekly for one hour on an ongoing basis to familiarize residents with current events and to promote mental stimulation and awareness. The sessions, attended by 12 residents on average, opened with a statement of the name and purpose of the group. The leader then read two or three news articles, followed by two or three human interest or humourous articles. Although no formal post-implementation evaluation has been conducted, it

appears most participants did not acquire new information from the sessions. However, they enjoyed the groups and were mentally stimulated.

Carey and Hansen (1986) concluded that during both groups, participants showed improved social skills, and increased self esteem, alertness, and orientation. However, this higher level of function was not maintained outside the group. The success of such groups therefore lies in the quality of interaction within the group, the quality of the moment, and the goals of the groups must be reformulated to reflect the short term.

o A nursing home designed for cognitively-impaired old people

Lawton, Fullcomer and Kleban (1984) describe a post-occupancy evaluation of a prosthetically designed nursing home, the Weiss Institute in Philadelphia. The 120-bed skilled nursing facility was planned by the Philadelphia Geriatric Center to serve moderately and severely impaired old people with Alzheimer's disease and other organic brain impairments. Features included variations in room decor, colour coding, graphics and large orienting stimuli. Rather than the typical double-loaded corridor design, the architects created a very large central area measuring about 40 feet by 110 feet with bedrooms on the periphery, opening onto the central space. It was hoped this arrangement would enhance orientation, since most important areas of the facility could be viewed from any vantage point. Also, it would create a space where interactions among people might be enhanced and it would allow residents to watch others engaged in various programmed activities and perhaps encourage them to join.

Surveys and observations after seven months in the new building found that staff and relatives strongly approved of the central area, except for the noise there. The floor was hard terrazzo, a public address system was installed and the open-plan diffused sound and masked communication. The visiting rate doubled in response to the more pleasant surroundings (compared with the old facility) and the increased privacy afforded in the two-bed rooms that replaced the four-bed rooms.

Patient-care activities were reduced, perhaps because the nursing station in the central area allowed staff to view patients easily and they did not need to approach them. Heightened visibility and surveillance capacity reduced face-to-face interaction.

Residents participated more in planned or staffed activities and exhibited less pathological or stereotypic behaviour. Use of the bedrooms decreased, in favour of occupancy of the central space. Social behaviour did not change, although it was hoped it would increase. Residents had more opportunities for privacy, and in the more spacious surroundings were less likely to

come close to others. The researchers also noted that many months had elapsed between the times the residents were observed, and social behaviour usually decreases as dementia advances. No changes occurred in use of restraints, time in passive behaviours, and time spent moving around.

o Establishment of a dementia unit in a nursing home

Grossman et al. (1986) describe the development of a special unit at the Hebrew Home for the Aged in Riverdale, New York. Three studies were undertaken before a decision was made to form the unit. First, clinical care staff of the home's skilled nursing units were asked whether they believed they could offer patients better care in special units and whether patients would be more comfortable there. Seventy-six per cent answered affirmatively to the first question; and 83 per cent, to the second. The Residents Council's input was solicited, and its support of a separate unit was confirmed by interviews with 24 randomly-selected residents in the skilled nursing units. Finally, DMS-1 scores (scores on an assessment tool used to determine eligibility for Medicaid admission to nursing homes in New York) were reviewed for the previous five years to document whether the patient profile of the home was changing, to include more severely cognitively impaired. Staff were also polled on their perceptions, and residents were tested on activities of daily living. These measures confirmed the belief that the home was accepting an increased number of patients with dementing illnesses, and helped determine current levels of need for special care.

The building containing the largest number of demented patients was selected as the site for the new unit, to help minimize patients' confusion during the transfer, and all patients in the building were assessed by the nurse and social worker for eligibility. The joint assessment balanced the nurse's evaluation, related to day-to-day function and illness, against the social worker's more optimistic, supportive evaluation.

The 44-bed special unit was designed to be protective, orienting and anxiety reducing. Many environmental modifications, such as colour coding of doors, were nominal in cost. Programmatic and staffing consistency were thought essential to a therapeutic milieu. Rotation of nursing and other personnel was discouraged and activity times were fixed, to encourage orientation. A typical day could include a sensory integration group, sports activities, exercise programming, active socialization activities and communication groups.

Evaluation of the unit indicated specialized staff training was a costly but essential element in establishing a special care unit. Daily 15-minute staff meetings with supervisors were also

important, to allow all staff to vent their feelings and discuss problems. Unit staff and staff on skilled nursing units said they were able to offer better care under the new arrangement.

Patients on the special unit also appear to have benefitted. Indicators include a decrease in the average number of accidents each month, from 16 during the six months before the unit was formed to 10 during the unit's first four months. The number of screams has decreased from 18 to 20 every five minutes during the unit's initial weeks, to three to six screams every five minutes when counted six months later.

5.3 Support Groups for Caregivers

The goals, composition, and structure of family support groups vary widely. Some groups are organized solely for self-help and support, while others focus on education or psychotherapy, or a combination of these. Some groups meet for a specific number of sessions and others meet indefinitely; some are led by professionals and some by peers. Membership may be restricted to primary caregivers, or spouses or any family members (Glosser and Wexler 1985). They may be closed after the first one or two sessions, or new members may join at any time.

The group may be organized through a treatment facility, a social service agency, a day care or other organization.

The support groups for caregivers most frequently discussed in the literature are structured series of eight to 10 sessions sponsored by a medical facility or social service agency. The sessions usually follow a predetermined program covering such topics as the nature of dementia, patients' behaviour, legal and financial considerations and community resources. Group members usually are encouraged to contribute their experiences in these areas and to participate in open discussions. Members usually value the group experience for its educational component, the emotional support offered by other members, and its practical advice on caregiving. At the end of the series, caregivers may continue to meet as a self-help support group, and the formation of such a group may indeed be an objective of the formal program.

Four examples of professionally-led support groups are described here in detail; three were selected in part because they have been formally evaluated and their effects on caregivers can therefore be discussed. Little systematic research has been done on the effectiveness of support groups, and much that is available lacks reference to controls or relies solely on participants' evaluations of the program (Haley, Brown and Levine 1987; Glosser and Wexler

1985). A more complete discussion of the effectiveness of support groups and other dementia programs in relieving caregiver stress is presented in Section 6.

5.3.1 Examples of professionally-led support groups

Five professionally-led support groups described in the literature (Exhibit 5.7) provided both information and emotional support to participants. In general, each session comprised a lecture followed by a group discussion; as participants began to feel more comfortable with each other as the sessions progressed, the lecture content decreased and more time was devoted to discussions of personal experiences and concerns.

The program offered through the University of Alabama was structured so as to permit evaluation of its effectiveness. Participants were assessed on measures for depression, life satisfaction, feelings towards the patient, social activity and coping responses; they also evaluated components of the program. Paradoxically, participants consistently rated the programs favourably but failed to show any significant change in psychological or social functioning after participation, compared with a control group. Researchers suggested that methodological factors may have made it difficult to detect changes. Participants differed markedly in their levels of distress at the outset of the program, and this heterogeneity made it difficult for the group mean to show improvement. Also, benefits of the program may not become evident until after the four-month test period. Outside events such as changes in the patient's or caregiver's health also made it difficult to identify changes in the caregiver related to the program. Finally, the researchers observed in the groups that caregivers needed concrete assistance, such as chore services, in-home health care and respite care, which they could not afford. The families needed more comprehensive, coordinated social, medical and health services (Haley, Brown and Levine 1987).

The evaluation of the program offered through the University of Southern California found reduced levels of burden between experimental and control groups, although researchers cautioned that the reduction could be caused by other factors (Kahan et al. 1985). Participants may have become overly confident and optimistic about their situation as a result of new knowledge and skills; they may also have been simply responding to the concern shown to them by professional staff. Levels of depression among caregivers were reduced, reflecting more a change in mood than changes in symptoms of clinical depression. Acquisition of new knowledge was important in reducing burden and depression.

Lectures were presented by staff members who knew some of the caregivers and their families through previous evaluations at an associated clinic. This knowledge helped them to present

material informally, relating it to participants' experiences, and to look beyond the question asked by a participant and respond to underlying emotional concerns.

Exhibit 5.7 Five Professionally-led Support Groups

	University of Alabama	Rehabilitation Research and Training Center on Aging, University of Southern California; Older Adult Health Center
Parent Organization	University research group	Health centre and research group
Other Services Offered	None indicated	None indicated
Leadership	Clinical psychologist and graduate student	Clinical psychologists
Group Size	5 members/group, 31 participants (9 controls in evaluation study)	22 in group (18 controls in evaluation study)
Duration	10 1.5-h sessions (7 weekly, 2 two weeks apart, 1 one month later)	8 weekly 2-h sessions
Topics (in order of presentation)	Cause of dementia Behaviour problems Home nursing care Use of outside resources Community resources Caregivers' emotions and stress management Four open sessions	Medical aspects of dementia Normal problems and family reactions Behavioral management Medical concerns Stress management Legal issues Developing a helping network
Evaluation	No measurable change in caregivers' functioning and quality of life, but high levels of expressed satisfaction with program's information, problem-solving and emotional support aspects	Participants showed measurable decreases in burden and depression, and increases in knowledge

Exhibit 5.7 Five Professionally-led Support Groups (Continued)

	University of Massachusetts Medical Center	Philadelphia Geriatric Center, Pennsylvania
Parent Organization	Medical centre	Geriatric centre
Other Services Offered	None indicated apart from medical services	Respite care program
Leadership	Neuropsychologist and geriatric social worker	Social worker or psychologist
Group Size	10-20/group; 104 started program and 54 evaluated it	15-30 participants
Duration	8 weekly 2-h sessions. Open support group formed to continue sessions	10 weekly 2-h sessions; group decides whether to continue afterwards
Topics (in order of presentation)	Members' own experiences Nature of dementia Behavioral problems/management Community resources Legal/financial issues Nursing home placement Caregivers' feelings	Medical aspects of dementia Medical care Patients' behaviour Behaviour management Sources of stress for caregivers Stress management Planning for future care Self-help
Evaluation	Participants evaluated program very positively; emotional support and sharing, medical information and practical tips were most valued	Participants cited as benefits: recognition they were not alone, sharing of information, and mutual support

Exhibit 5.7 Five Professionally-led Support Groups (Continued)

	Fairfield Health Centre, Victoria, B.C.
Parent Organization	Geriatric care centre
Other Services Offered	Assessment, day hospital, psychiatric care for in-patients and out-patients
Leadership	Medical social worker
Group Size	2-7 participants/session; 26 participants in total
Duration	Open-ended; 1 1/2-h weekly sessions
Topics (in order of presentation)	Topics selected by participants, based on their needs. Stress management and depression were important.
Evaluation	Participant evaluations every three months guided leaders on subsequent sessions.

Participants evaluating support groups through the University of Massachusetts Medical Center rated the sharing of problems and feelings with others most highly, followed by educational aspects (Glosser and Wexler 1985). The least positive evaluations were given to various aspects of the program intended to help reduce family conflict and decrease loneliness and isolation. Participants also indicated information on nursing homes, community resources and legal/financial matters was very helpful but not as helpful as other aspects of the program.

The researchers believed these areas of concern required more individualized interventions such as family therapy, individual therapy and individual casework; group leaders found they were spending two to three hours weekly in individualized casework and some participants returned one or two years after the program for help with immediate problems. The researchers concluded that the ultimate success of support groups depends on their inclusion in a broader service network.

The Philadelphia Geriatric Center's project had a goal to establish 30 self-help groups in 30 months (Reever 1984). At the end of a 10-week session, groups decided whether to continue on their own, with some support from the centre and the Alzheimer's Disease and Related Disorders Association. Program organizers observed four stages in group development:

- Information gathering. Many participants have just received the diagnosis and are hungry for information, although they cannot assimilate it all.
- Emotional sharing. Group members share their fears and frustrations; information on the disease, coping and the future is important but some showed resistance to the diagnosis, new caregiving techniques or support services.
- Mutual support. Group members gradually turn to each other, not the formal leader, for support and opinions.
- Self-determination. Members have adjusted to being caregivers and re-evaluate group goals to include new goals such as advocacy, recruitment and program planning.

Groups rarely moved smoothly from one stage to the next but rather vacillated between stages or were held up at one or another stage. To promote the transition to a self-help group, the program employed strategies to create cohesion among members, empower them as caregivers, create a belief in the positive benefits of the group, and foster confidence in members' ability to run a group.

Although the program was not formally evaluated, 20 of the 30 groups continued as self-help groups. Participants identified the following as benefits of the initial 10-week sessions: recognition they were not alone, information sharing, and mutual support. Leaders believed many members used new, more effective management techniques; showed more confidence; took new interest in activities outside caregiving; and used respite care and other services more often. However, some caregivers refused to adapt to their caregiving role; they had seemingly exhausted their old resources, had turned to the group for advice and information, but had been unable to change themselves or their families so as to use any new approaches.

A somewhat different example of a support group is the Alzheimer's family/patient group program for caregivers and outpatients of the Gerontology Center of the Albert Einstein College of Medicine in New York (Aronson, Levine and Lipkowitz 1984). The groups meet weekly for 1.5 hours; at each meeting patients and caregivers join for a general orientation discussion and presentation of the session plan, plus a brief exercise-to-music period. The two groups then separate for about 45 minutes; the patients socialize while caregivers have group discussions on various topics. The sessions appear to be on-going rather than a limited series, and always open to new members, since the membership criterion is outpatient status. Centre staff seem to play a leadership role.

Researchers believe the program is meeting the needs of members. Most members attend all meetings and many socialize between sessions. Some members have been helped through the decision to place a patient in an institution (and continue as caregiver group members) and others have resumed personal activities.

A similar support group is available to caregivers of patients being treated at the Fairfield Health Centre in Victoria, B.C. (Read and Hamlet 1987). Program organizers believed caregivers were more receptive to information and meeting other caregivers while their patient was being assessed and treated, a period of crisis or disequilibrium in the relationship between caregiver and patient. A content analysis of the sessions showed that patient management (i.e. coping with personality changes) and the stress of caregiving were the topics most frequently discussed, from both a practical and emotional perspective. Most of the group time was spent in non-directive sessions on emotional and relationship issues, although some didactic sessions were held. The group, which included caregivers to patients with multiple physical and psychiatric disorders, expressed a need for education about dementia, depression and stress management, plus information about community resources to help plan for the patient's discharge from the treatment program at the health centre.

After a year of operation, two groups within the 26 participants become apparent. The largest group was participants who attended one to six sessions to obtain specific information and limited ongoing support. The second group sought longer term emotional support from each other, particularly during crises. These five women each attended an average of 25.6 sessions.

The support group has been reorganized into a time-limited, eight-week program with one month between programs to regenerate demand. The new format allows the health centre to focus on short-term support and education, and participants to reassess their needs and explore new sources of support. A community-based network of support groups has been formed in Victoria and through it, long-term participants in the health centre's program have joined neighbourhood-based groups. The network is supported by a newsletter and a committee of caregivers, group facilitators and advisors.

A psychotherapy group for caregivers in Portsmouth, England is another example of a caregiver support group (Nusberg 1984). A physician leads the eight- to ten-member group that meets weekly for an hour to talk about feelings and vent anger, frustration and guilt. Organizers say caregivers leave the group with renewed strength, feeling relieved that their problems have been aired.

A National Council of Carers has been active in the United Kingdom for about 25 years. Its 15 branches provide social support to caregivers and try to ensure that its members receive the allowances and respite services to which they are entitled (Neysmith and Lewis n.d.).

5.3.2 Issues and problems in caregiver support groups

The issues listed below were identified in the literature.

- Group composition

Support groups may include a variety of participants: spouses, children or other relatives, several members of the same family, caregivers to patients in institutions, caregivers to community-dwelling patients, caregivers to early or advanced cases of dementia, or even non-caregivers. Groups that mix caregivers to patients in the community and in institutions, or groups of caregivers to patients at various stages of dementia, appear to work well (Glosser and Wexler 1985; Gates and Marshall 1987; Steuer and Clark 1982; Simank and Strickland 1986). Caregivers to patients in the earlier stages of dementia found that observing the problems of caregivers to patients at later stages gave them a realistic indication of the problems they

could expect in the future. Participation of several family members in the same group furthered family cohesion and support in families where the pre-existing relationships were good and exacerbated relationships in families in cases where members disagreed on the patient's treatment (Kahan et al. 1985).

Caregivers who had already placed their patient in an institution could support group members just facing this decision. However, some caregivers may be unable to cope with hearing others' problems and viewing their own future; these caregivers may be using denial and other defenses against anxiety and may not benefit from group participation (Steuer and Clark 1982).

Similarly, participants assimilate and accept new information at different rates, and the pace of presentation must respect the participants' ability to adjust.

A group comprising professionals interested in dementia and caregivers to dementia patients failed to become a cohesive support group for the caregiver participants, unlike a similar group only of caregivers, suggesting such mixed groups cannot meet caregivers' emotional needs (Simank and Strickland 1986).

o Open-ended or time-limited groups

Shibbal-Champagne and Lipinska-Stachow (1985) believe open-ended groups are not as effective as time-limited groups (operating for a set period) because the former are often marked by low levels of participation and eventual disintegration. A planned program structured around group tasks over a set period seems to help participants develop supportive relationships that can sustain them in an open-ended group formed once the time-limited group process is finished. The open-ended group also helps caregivers with on-going and new problems that arise as the disease progresses (Glosser and Wexler 1985). Time-limited groups also have closed memberships, and therefore caregivers seeking group support and information must go on a waiting list, regardless of immediate need (Gates and Marshall 1987).

o Groups as part of a range of services

Support groups cannot meet all needs of caregivers; they must be part of a range that includes such services as respite care, in-home health care, homemaker services and various types of family and individual counselling (Glosser and Wexler 1985; Wasow 1986).

o Therapy vs. support

Although it may be healing for caregivers to examine their anger and guilt, many are already living at their emotional limits and cannot endure more upset. In any event, caregivers in groups usually resist therapeutic interventions initiated by the group leader (Wasow 1986; Winogrond et al. 1987).

o Group focus

Sometimes caregivers need a break from discussing their patient and their problems, but it is not always clear when. Many caregivers may have few other outlets, apart from the support group, and few other opportunities to socialize (Wasow 1986). Opportunities to socialize within the support group may thus be important.

o Self-help groups

The Philadelphia project designed to initiate self-help groups identified several obstacles to maintaining groups. New groups may become overly dependent on guest speakers to fill meeting time, rather than allowing for group discussion. Such discussion builds the group cohesion needed to ensure the continuance of the group. Also, a change in leadership can derail a group, since the leader provides continuity. Finally, groups have high turnover in membership and recruitment of new members requires constant and intensive effort (Reever 1984).

5.4 Other Interventions for Dementia Patients and Their Caregivers

Families caring for a dementia patient need concrete assistance with the problems of daily care plus information about dementia to help plan for the future. They also require emotional support to cope with the loss of their loved one and the stresses of caregiving. Thus both clinical and social interventions must be available simultaneously; several are described by Cole, Griffin and Ruiz (1986).

5.4.1 Clinical interventions

In most cases, clinical interventions should focus on enhancing the caregivers' abilities to cope with the care of a patient. This focus likely requires an assessment of the caregivers' ego strengths and coping skills and interventions that bolster self-confidence and self-esteem.

o Individual counselling

Counselling can be used to help in decision-making, to teach caregivers how to manage patients' behaviour more effectively, and to plan for long-term care. Caregivers also need an opportunity to vent frustration, grief and anger; if unrecognized and unresolved, these feelings can seriously impair the caregiver's ability to cope with caregiving stress.

Through individual counselling, the social worker can advise caregivers on how to manage difficult behaviours and may arrange nursing consultations for physical care problems. Education and support groups focusing on management techniques may be a valuable supplement to individual counselling.

o Family counselling

Family counselling is an effective means for various family members involved in patient care to make key decisions without conflict. Siblings may differ in their concept of adequate care and in their ability to offer financial and emotional support, and the social worker must remember in the ensuing conflict that the welfare of the patient and the caregiver are of primary concern, not the relationship among family members. Counselling also helps adult children reach agreements with their parents on appropriate care; conflicts may arise because children tend to be concerned with safety while adults wish to preserve independence for as long as possible.

An example of family counselling is provided by a veterans' hospital in Bedford, Mass., which has developed a practice of routine, periodic conferences with families of Alzheimer's disease patients admitted for long-term care in the hospital's diagnostic and treatment centre (Fabisewski and Howell 1986). Topics addressed by the hospital's multi-disciplinary treatment team include information about the disease, treatment regimens, and patients' behaviour. Guidelines for medical intervention during life-threatening illnesses are also developed. Family members are encouraged to express and identify conflicting emotions and the treatment team offers guidance, support, and positive reinforcement of coping skills.

o Short-term small group therapy

Caregivers' feelings about the patient, caregiving and changes in their lives as a result of caregiving can be examined and resolved in the group, reinforcing the caregiver's confidence in problem-solving. While group members provide each other with feedback from a variety of perspectives, the primary role of the social worker is to maintain a focus on improving daily

functioning and problem solving abilities. Participants who want to resolve unrelated, long standing conflicts could be referred to long-term individual or group therapy.

5.4.2 Social interventions

Various social interventions can assist caregivers with legal and financial matters and long-term planning.

o Legal advice

Legal problems are especially of concern to elderly women, who often have had little experience in these matters. Usually, legal problems can be resolved quickly by a knowledgeable lawyer.

o Financial planning

The long-term costs of care can be difficult to carry, and a financial plan is needed to budget wisely, protect assets and provide for future costs.

o Long-term care planning

A frightening situation may become more manageable through evaluation of possible care options before a crisis or a need for action arises. Provision of accurate medical information on the characteristics of the dementing illness and its progress can help families accept the diagnosis and plan for appropriate levels of care. If no diagnosis has been made, the information may encourage families to obtain a complete evaluation, to rule out any reversible cause of the dementia.

o Centralized access to information about community resources

A person knowledgeable about the needs of dementia patients can help caregivers define their needs and choose from available resources. The New York City Alzheimer's Resource Center helps Alzheimer's patients, their families and others find appropriate services and programs in the city (Cheek 1987). Funded by the City of New York and a private foundation, the center primarily assists family caregivers through referrals to medical diagnostic centres and guidance on public benefits and other sources of support. The centre also offers free individual short-term counselling for caregivers, help with nursing home selection, and legal and financial planning assistance for persons who cannot afford to pay a lawyer. Three publications have

been prepared by the centre: one on caring for an Alzheimer's patient at home, and two on resources available in the city and through the state and nation-wide agencies.

o Alzheimer's registry

Most Alzheimer's patients wander, and may be found riding aimlessly on city buses or wandering in public places. Police may be requested to help a caregiver locate a patient, but many caregivers hesitate to ask for help, viewing the incident as a failure in their duty. Setting up a registry with police or other officials can reduce the embarrassment of losing the patient since it recognizes the pattern of behaviour among Alzheimer's sufferers; it also facilitates the work of police who come upon an unreported "missing" person. Such a registry has been set up by the RCMP in Manitoba, for example. The registry includes a physical description of persons with Alzheimer's disease, and names of individuals who may take custody (MSOS 1988).

6.0 EVALUATIONS IN THE LITERATURE ON PROGRAMS

This section discusses the following special issues in dementia programs and respite programs:

- What aspects of dementia programs and respite programs are the most effective in relieving caregiver stress?
- What aspects of dementia programs are the most beneficial to dementia patients?
- What programs are the most effective in helping elderly people to stay in their own homes?
- Are there programs that address the needs of persons with dementias who have no family or surrogate caregiver?
- Are there identifiable community prerequisites to the establishment of effective dementia programs and respite programs?
- What are the future trends in respite care and service provision for elderly persons with Alzheimer's disease and related dementias?
- What guidelines, standards and legislation govern dementia programs and respite programs in other jurisdictions?

6.1 What Aspects of Dementia Programs and Respite Programs are the Most Effective in Relieving Caregiver Stress?

There has been little or no research on the effectiveness of the various programs and services designed to support dementia patients and their caregivers (Ory et al. 1985; Niederehe and Frugé 1984). In most cases, self-reporting of program benefits or staff perception of benefits is the basis of program evaluations. In studies incorporating some objective measures of caregiver burden (Haley, Brown and Levine 1987; Pratt et al. 1985), participants showed no measurable change as a result of participation but placed high value on the program and cited its benefits for their patients or themselves.

6.1.1 Respite care

Few formal evaluations of in-home and institutional respite care were found in the literature, although descriptions of the programs discussed in Section 5.0 and general discussions of caregivers' needs in the literature cite such respite programs as providing needed relief to caregivers. The University Hospital program of intermittent respite admissions and day hospital attendance in Saskatoon, for example, was described as providing caregiver relief (Dunn, MacBeath and Robertson 1983). Similarly, intermittent admission to a nursing home in California (Ellis and Wilson 1983) was viewed as a refreshing change by both caregivers and many patients.

Research in progress at McMaster University in Ontario found that caregivers receiving an experimental caregiver support program showed a clinical improvement in their quality of life over a six-month period (Mohide 1988, personal communication). Thirty caregivers were provided a support program that included in-home respite, caregiver-focused health care, education about caregiving and dementia, assistance with problem-solving and participation in a self-help support group. Thirty controls were provided conventional nursing care. At the end of the study period, no difference in anxiety and depression was found between the two groups, but quality of life measurements had increased for the experimental group and decreased for the control group.

Effects of adult day care on caregivers are not well documented, with much of the evaluation of these programs examining effects on patients. Caregivers evaluating the Atlanta day care program described in Section 5.0 (French 1986) said they benefitted from relief from physical and emotional stress; relief from worry about patient safety and loneliness; time for other activities; and relief from guilt about the quality of care the patient received at home.

Gilleard (1985) evaluated the effects of adult day care service on 129 caregivers, using standard measurement instruments to assess levels of emotional distress among caregivers and factors contributing to distress before patients' admission to the program, three to four months after admission, and six to seven months after admission. Caregivers whose patients remained in day care throughout the entire period showed significant reductions in distress, although no significant changes occurred in the levels of problems presented at home by the patients that contributed to distress. Caregivers whose patients obtained long-term institutional care during the study period showed the greatest decrease in distress and those whose patients stopped attending or never attended showed the least decrease. Researchers concluded that day care attendance reduced levels of distress for most caregivers. However, at least one-third experienced no reduction in distress and admission to a long-term care

facility ensued. Most of these caregivers believed nothing could have delayed the admission and viewed it as beneficial.

Evalusearch Research Consultants (1985), in an evaluation of a senior day program operated by the Alzheimer Society of Ottawa-Hull, found that dementia increased among program participants but caregivers' burden decreased or remained the same in most cases. Instruments measuring dementia and caregiver burden were administered at intake to the program and six months later. Complete data could be collected for 18 of the 45 persons who participated in the program during the study period; in most cases, data for the others were incomplete because the program participant was not in the program for the full six months or staff believed testing would have a negative effect on the participant. In 12 cases, caregiver burden decreased or was maintained at the same level while the patient's dementia increased; in three cases, burden decreased as dementia remained unchanged and in another three cases, both burden and dementia increased. The researchers concluded that the program had assisted two-thirds of the cases.

6.1.2 Caregiver support groups

Research projects measuring changes in burden among support group participants yield mixed results. Haley, Brown and Levine (1987) and Pratt et al. (1985) found no measurable change in burden among participants, although participants highly valued the program. The researchers noted methodological factors and other aspects of the caregivers' lives (i.e., the need for concrete assistance) could account for unchanged levels of burden. Kahan et al. (1985) found reduced levels of burden among group participants but suggested this reduction could be brought about by other factors, such as undue optimism among caregivers.

Jenkins, Parham and Jenkins (1985) speculate that support group attendance helped decrease burden in a study of 120 caregivers. Support group attendance was lowest among caregivers in the first year after diagnosis and peaked among caregivers with a patient at home two or more years after diagnosis. After institutionalization, attendance declined. Comparing levels of burden, patient dementia and support group attendance, the researchers found that as attendance and dementia increased, burden decreased, suggesting that attendance was helping caregivers adapt to some extent to a stressful situation.

More subjective measures of the effects of group programs include participants' and leaders' evaluations. Winogrond et al. (1987) believed some caregivers' coping skills improved during a six-month study period, although some participants became more distressed. Group leaders in a Philadelphia group program (Reever 1984) believed caregivers exhibited more and different

coping techniques, increased confidence in their decisions concerning patient care, increased use of community services, and greater interest in outside activities. The caregivers reported as benefits: recognition they were not alone, sharing of information, and mutual support.

Fifteen members of a support group for Alzheimer's disease found the group most helpful in improving their knowledge of the disease, which in turn led to more appropriate expectations and less guilt about the patient's behaviour (Barnes et al. 1981). The second most beneficial aspect was the sharing of feelings and subsequent sense of support and acceptance of other caregivers. The researchers observed that group participation also reduced isolation and, during the group, members were urged to take better care of themselves. Members also pooled practical caregiving tips and assisted each other with legal, financial and social problems. Although this group had few members, their perception of the value of the group is shared by others. Wasow (1986) comments that the value of support groups in terms of their educational component, opportunities for self-help and sharing, and practical tips on caregiving is well-established.

6.2 What Aspects of Dementia Programs Are the Most Beneficial to Dementia Patients?

6.2.1 Therapies

The benefits of various therapies used to treat dementia patients in institutions, or sometimes used in dementia programs for patients living in the community, cannot be ascertained because of methodological difficulties with most research in this area. Zarit and Anthony (1986) observe that evaluation of therapeutic interventions is difficult because often the goals of the intervention are inappropriate, addressing the negative effects of the environment or some other intervention (i.e., drug therapy) that could better be resolved through other means. More appropriately, goals should seek to maximize patient function within the limits set by the underlying condition of the brain. Also, studies lack adequate control groups and do not indicate whether the subjects in the sample group suffered from dementia, how it was diagnosed and whether more advanced cases were excluded. Measurement of outcomes is difficult because standard instruments are unreliable and staff ratings and self-reports are biased. Finally, most studies omit long-term follow-up to see whether therapeutic gains are maintained.

With these cautions in mind, Zarit and Anthony (1986) examined the efficacy of various patient therapies used in institutional settings; these therapies are also used in some programs for community-dwelling dementia patients.

o Behaviour modification

This therapy is commonly attempted in institutions with incontinent patients but is not very effective. Staff may be unfamiliar with dementia and offer inadequate or too infrequent reinforcers; dementia patients may be unable to learn new behaviours or to respond to reinforcements offered by researchers.

o Individual and group psychotherapy

No controlled studies of the outcome of psychotherapy have been done. Its main value may be that it identifies persons with depressive symptoms or persons who have withdrawn because of lack of stimulation or other problems in the environment.

o Reality orientation

Reality orientation reorients the confused patient to person, place and time through small group meetings or through on-going, 24-hour efforts of institution staff. The results of studies of reality orientation are ambiguous, given their methodological problems and inconsistent findings from one study to another. Zarit and Anthony (1986) note it has never been demonstrated that patients are better off if they know who and where they are. However, staff seem to rate patients more positively after the therapy, perhaps because it gives them a more positive outlook on patients.

o Environmental changes

These include manipulation of the physical environment, staff/patient interactions, and organization of the institution. These interventions seem to hold promise but have not been thoroughly assessed.

6.2.2 Adult day care centres

Evaluations of adult day care centres often comment on their effects on patients, perhaps because centre programs are perceived, at least in part, to be therapeutic. For example, day care programs often incorporate reality orientation and other therapies in their programs. More generally, program sponsors hope that through increased socialization and activity at a day care centre, patients' isolation and resultant cognitive and behavioural difficulties can be reduced (Fisk 1983). Also, functional losses due to neglect or depression (rather than due to

cognitive loss) can be avoided or delayed by centre activities. For example, staff can teach patients toileting or hygiene if caregivers are reluctant or unable to do so.

Evaluations of day care programs have found generally that patients' cognition continues to decline, but behaviour and socialization stabilize or improve. Fisk and Pannill (1987) observed that increased socialization through day care also appears to help reduce depression.

Panella et al. (1984) and Winogrond et al. (1987) measured patients' cognitive abilities at several points during day care program participation and concluded that cognitive ability declined over time. Winogrond et al. (1987) found that despite significant declines in patient cognitive function over six months, behaviour problems did not increase significantly.

More subjective evaluations include family evaluations of the Atlanta day care program described in Section 5.0 (French 1986), in which families said patients' benefits included better sleep at night, increased self-esteem, more out-going behaviour, increased co-operation, a chance to socialize with peers and increased happiness. In the survey of day care centres (Mace 1984a), 71 per cent of centres reported dementia patients became less agitated and 67 per cent reported the patients paced and wandered less. Also, 84 per cent reported that dementia patients formed special friendships with others, spending the day together as a couple. Similarly, Rosin et al. (1985) believed restlessness, agitation and wandering were modified by participation in a club program in Jerusalem, Israel.

6.3 What Programs Are the Most Effective in Helping Elderly People to Stay in Their Own Homes?

Family support is the most important factor affecting the ability of elderly, demented persons to remain in the community. Although the objective of many home support services is to help the family and caregiver care for the patient in the community for as long as possible, little research has been conducted concerning the factors that precipitate placement in an institution and appropriate intervention strategies to reduce these factors (Ferris et al. 1987). However, many service providers believe that day care and other respite care plus counselling and support groups do forestall institutional placement.

Caregiver characteristics and caregiver well-being appear to be important predictors of placement of a patient in an institution. In a one-year study of 209 caregivers in North Carolina, those caregivers most likely to turn to an institution were female, employed, and younger than the other caregivers, with an average age of 55 compared with 65 (Colerick and George 1986). Most were adult-child caregivers who reported above-average incomes, high

levels of stress due to multiple role demands and dissatisfaction with recreational pursuits. These caregivers appeared to investigate all potential sources of relief before placement; the increased use of stress-reducing drugs after placement attests to continuing feelings of burden. The least willing to consider institutional placement were spouse caregivers, often old and frail themselves. Their patients occupied a central role in their lives and they believed assistance with caregiving was unnecessary. Acceptance of their role and belief in their efficacy as caregivers contributed to higher levels of life satisfaction than expressed by caregivers seeking institutional placement.

Similarly, Gilhooly (1986) found in a study in Scotland that the degree of relationship between caregiver and patient and the quality of the relationship were significantly associated with attitudes towards institutional placement. Comparing 24 caregivers who lived with their patient (a group including all spouse caregivers and the more impaired patients) and 24 caregivers who lived separately (a group including 12 with other dependents and 15 employed), the researcher found the spouses were committed to continuing home care "until death do us part". The value system or attitude of the caregiver to institutional care was also found by Kraus (1984) to be an important factor in some caregivers' perception of burden and decision to keep a patient at home.

Gilhooly (1986) also found that caregivers who lived separately from the patient were more favourable towards institutional placement, perhaps because of the effects of continuing care in the community -- moving the patient into their own home, disruption of employment, and upset in their family. She found no correlation between caregiver well-being and preference for institutional care, although Hassinger (1985) found specific aspects of caregiver burden (anger, dependency of the patient, and lack of privacy) were good predictors of institutional placement among all types of caregivers.

Findings on the relationship between the patient's condition and institutional placement are mixed. Colerick and George (1986) found that no patient characteristics, including diagnosis, duration of illness, symptoms and severity of symptoms, were significant predictors of institutional placement. Gilhooly (1986) found no correlation between length of care or level of impairment and preference for institutional placement, cautioning that the study sample (drawn from a day hospital) may be biased to exclude patients whose condition necessitated institutional care. Finally, Fisk and Pannill (1987) found that of 267 dementia patients in their U.S.A. study, those who went to nursing homes were only slightly more impaired cognitively than those who stayed home, and there was no difference functionally. The patients who went to nursing homes and the patients who stayed home differed in terms of the presence of a caregiver spouse and other factors.

However, Hassinger (1985) found severity of dementia and aspects of caregiver burden to be good predictors of institutional placement. (Burden and severity of dementia were only weakly correlated.) Mac Fadgen (1987) found that dementia patients on community service caseloads in Metropolitan Toronto and the Region of Peel were less impaired than dementia patients in long-term care facilities. Also, Kraus (1984) found in a survey of 119 dementia patients in Kingston that in comparison with caregivers with a patient in the community, caregivers for patients placed in institutions were far more likely to report extreme patient behaviours; 67 per cent of these caregivers reported behaviours such as violence, compared with 1 per cent of caregivers to community patients. Ferris et al. (1987) found that patient behaviours such as violence, incontinence and wandering, and the effects of these behaviours on the caregiver, were often associated with institutional placement and that the length of the illness and the patient's dependency particularly seemed to wear down the caregiver. Costs of the illness, the need for auxiliary help and assistance from the social network also seemed to affect the decision regarding institutional care.[1]

Institutional placement of male and female patients is subject to different factors. Ferris et al. (1987) found in a sample of 1085 patients in New York that wives were more likely than husbands to place their spouse in an institution. Reviewing data on 109 patients, they found no differences in duration or severity of illness but found husbands were more likely than wives to hire auxiliary help. Only 14 per cent of husbands who placed their wives in an institution went without auxiliary help, compared with 39 per cent of wives who placed their husbands.

Colerick and George (1986) found that female patients have a much greater likelihood of being placed in an institution than males, although the relationship between sex and placement was not statistically significant. The finding supported other work indicating that women live longer than their partners and that male patients are more likely than female patients to be cared for by spouses. Female patients are cared for mostly by their daughters, who have difficulty managing employment, caregiving and responsibilities to their husband and children.

Have dementia programs demonstrated any ability to delay institutional placement? Neysmith and Lewis (n.d.) found an in-home respite care program in Hamilton was used primarily as a

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[1]Ferris et al. (1987) identified factors influencing the decision on institutional placement by interviewing caregivers and then using descriptive statistics to identify key factors. Other research (Gilhooly 1986; Hassinger 1985; Colerick and George 1986) employs regression analysis to study relationships among variables identified through interviews and standard assissment tests.

crisis management tool, rather than as a means of continuing community care. Of 18 caregivers using respite care, half had applied for institutional care before receiving respite care and half applied while receiving respite through the program. Respite care was thus a service which relieved some of the stress until institutional placement occurred.

Gilhooly (1986) found no correlation between use of services and preference for institutional care, although she notes there was not likely enough variation in caregivers' use of services to measure it accurately. Although most caregivers in her study had one or two days weekly at a day hospital, very few had use of home help, in-home nursing services or meals-on-wheels. However, it was certainly the researchers' impression during interviews that the available services were helping caregivers maintain their patient in the community.

A 1979 study by the National Association for Mental Health (MIND) in the United Kingdom found that hospital and residential home places were best used for short-term admissions for respite, assessment or rehabilitation. Waiting lists for long-term, permanent care were substantially reduced if short-term admissions were readily available, with discharge negotiated with caregiver at the time of admission (Nusberg 1984).

Similarly, the medical community in Copenhagen, Denmark hopes to contain demand for psychogeriatric hospital space through day hospital services. Patients' condition can be improved through proper diet, drug therapy, home nursing, weekend meal delivery and other services through the day hospital, reducing the need for hospital or nursing home care (Nusberg 1984).

Ferris et al. (1987) found that counselling can reduce factors precipitating institutional placement. After identifying factors that influence the placement decision, the researchers enhanced a counselling program with the following strategies to help caregivers with patient management:

- information about drug treatments for managing problem behaviour;
- support group and individual counselling;
- education about Alzheimer's disease and coping skills; and
- enhancement of the caregiver's social network.

Also, the caregivers were advised that auxiliary help was almost essential to continuing home care. Since most could not afford it, information about the most affordable private agencies was made available. Also, advice and referrals for expert legal and financial counselling were offered.

The enhanced counselling program was offered to 41 families who were seriously considering institutional placement but believed it could be avoided if support were available. At the end of six months, only one family had placed the patient in an institution, primarily because the patient had an accident and needed hospital care.

Apart from these formal studies of the effects of dementia programs, participants' evaluations and researchers' descriptions credit various programs with delaying institutional placement. Panella et al. (1984) report that 24 per cent of families using a day care program at the Burke Rehabilitation Center at Cornell University (described previously) believed they would have had to consider early placement in a skilled nursing or health-related facility if the program had not been available. Sands and Suzuki (1983) found that the day care offered by the Harbor Area Day Care Center in California (described previously) provided an alternative to nursing homes for patients in the early and middle stages of Alzheimer's disease or a related dementia, based on what families believed they would have done without the program. Aronson, Levin and Lipkowitz (1984) found that the caregivers in the mixed patient-caregiver program at the Gerontology Center of the Albert Einstein College of Medicine (described previously) believed the group helped them continue to care for their patient and forestalled institutional placement. Finally, Dunn, MacBeath and Robertson (1983) found that respite admissions supplemented by day hospital attendance at the University Hospital, Saskatoon, maintained in the community elderly disabled patients who otherwise would have required immediate institutional care.

However, this conclusion was challenged by Mary Shephard, of the Portland Veterans Administration Medical Center. In a letter to the Journal of the American Geriatrics Society following publication of Dunn, MacBeath and Robertson (1983), Shephard (1984) cautioned that in order to justify the expense of respite care, its supporters will be required to show respite decreases institutional placement and thus saves money.

> This proof of decreased placement will require a prospective controlled study of respite care versus no respite care. It will be a difficult study to design and will require an interdisciplinary approach. Respite care can be approached scientifically, and it is crucial that we do this quickly and carefully, because the numbers of persons who might benefit increase daily (Shephard 1984, 621).

Apart from the kinds of research described in this section, however, controlled studies of the effects of dementia programs on institutional placement have not been conducted. Caregiver characteristics, (i.e., sex, age, employment status), value systems, caregiver well-being, and the nature and quality of the relationship between caregiver and patient appear to be important predictors of institutional placement. The effect of the patient's condition on placement is

unclear. While there is little research on whether dementia programs help patients live longer in the community, participants and program organizers believe that they do help.

It should also be kept in mind that delay of institutional placement need not be viewed as the major or only purpose of dementia programs. These programs also appear to ease the burden on caregivers, a worthwhile program goal in and of itself (Zarit and Anthony 1986; Gilleard 1985).

6.4 Are There Programs that Address the Needs of Persons with Dementias Who Have No Family or Surrogate Caregiver?

Some persons with Alzheimer's disease and other dementias live alone in the community. Fisk and Pannill (1987) found that 45 per cent of the 159 Alzheimer's patients in their study lived alone. Without a family caregiver or other community caregiver, these individuals have difficulty in finding out about available services and arranging to use them (OTA 1988). Transportation is a problem. Informal care and coordination of care, often provided by family caregivers, is not available. Thus, patients alone in the community are disproportionately dependent on long-term care services such as nursing homes, and case management by public agencies.

The task force of the Office of Technology Assessment found that few programs were available to identify and assist persons with dementia living alone in the community, and little program information could be obtained. However, it described a program in Spokane, WA in which police, ministers, groups and others in the community were asked to watch for old people who may be ill and to refer them to a lead agency. A single, central process was used to screen applicants and determine eligibility for services from 15 allied community agencies (OTA 1988).

6.5 Are There Identifiable Community Prerequisites to the Establishment of Effective Dementia Programs and Respite Programs?

Reever (1984) found that the support offered to self-help groups in Philadelphia was important to their success. In many cases, neighborhood agencies co-sponsored a group and provided various supports: endorsement of the program, client referral, meeting space, publicity, and services for the patient. The neighborhood base of the co-sponsoring agency was also important, since the self-help groups were organized to serve a limited geographic area within the city.

The Alzheimer's Disease and Related Disorders Association (ADRDA) was instrumental in establishing several of the programs discussed here, as indicated in various program descriptions. San Diego's Alzheimer's Family Center, for example, was initiated by the local ADRDA chapter after its survey of local caregivers' needs. The local chapter worked with area health, day care, and social services to develop a plan for the centre (Sanborn 1986). In other cases, other agencies become important; for example, a task force of local organizations (home health agencies, hospitals, churches, community groups) launched the Senior Respite Care Program in Portland, Ore., after a year of planning (Dunn 1986).

6.6 What Are the Future Trends in Respite Care and Service Provision for Elderly Persons with Alzheimer's Disease and Related Dementias?

Creation of special units in nursing homes and special respite care programs for dementia patients is a recent and growing development in Canada and the United States. The task force for the Office of Technology Assessment commented (OTA 1988, 247):

> At this point in the development of dementia care options, the programs are highly individualized. Providers are trying different interventions and exploring innovative ways to reach clients and hold down costs.

This trend has generated some controversy, with those in favour arguing in part that specialized dementia programs serve the unique needs of dementia patients, needs that are different from those of cognitively intact persons, and will result in better care. Those who question special programs note that cognitively impaired persons and physically impaired persons share many of the same care needs, and that many impaired elderly have multiple disabilities. (The arguments are presented fully in Section 5.0.) Interviews with Canadian specialists outside Ontario also indicate a trend to specialized programs.

On a practical note, Mohide (personal communication, 1988) cautions that many areas may not have enough dementia patients and caregivers to support specialized programs. Program planners must carefully examine the size of the relevant population in their service area, and then estimate the proportion willing and able to use the special program. In the future, demographic change will increase the number of dementia patients in the community and more specialized programs will be supported.

At present, Mohide sees a trend towards provision of multiple services and programs to help dementia patients and their caregivers. By providing combinations of respite care, education and referrals, for example, the multiple aspects of the caregiving situation can be addressed.

While it appears that families today continue to accept responsibility to care for members, their ability and willingness to do so in the future may be reduced. Increases in geographic mobility, increases in the population over age 75, decreasing family size, changes in the role of the sexes and increased female employment, and high rates of divorce and remarriage may alter the patterns and require a re-orientation of services (Ory et al. 1985).

Mace (1986) says that various home and community programs have been supported to help keep patients in situations where the cost of care is less than the cost of institutional care, and where families manage without burning out. The best of these programs are also therapeutic. "I believe that our charge for the coming decade is to learn what we can do to rehabilitate patients, to enable them to live with their illness, to improve their function, to remove excess disability, and to improve their quality of life" (Mace 1986, 7).

6.7 What Guidelines, Standards and Legislation Govern Dementia Programs and Respite Programs in Other Jurisdictions?

Few regulatory standards for adult day care and respite care are found in the United States. Thirty-nine states have licensing laws for adult day care; regulations range from criteria for receiving public funding to specifications for staffing and services requirements. Respite care programs providing service in the home or elsewhere are largely unregulated by local, state or federal agencies. In general, only those programs that provide services under Medicaid[2] are subject to any regulation or performance monitoring (OTA 1988).

The task force of the Office of Technology Assessment reports it may be premature to develop guidelines and criteria for special programs and nursing home units geared towards persons with dementia. The task force commented (OTA 1988, 259):

> Indeed, guidelines or standards could freeze into place approaches that may later prove less than optimal, or could block experimentation with other interventions. Further clinical experience and the replication of the most successful programs are needed.

However, knowledge about geriatric patients and the nature of dementia, plus common practices and approaches in special dementia programs suggest some common goals for good

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[2] Medicaid is a joint federal/state medical welfare program intended to provide medical and health-related services to low-income persons. In some states, Medicaid covers adult day care and in-home services; respite care and custodial care usually are not covered.

practice, such as prevention of excess disability and enhancement of remaining function. (These goals are presented in Section 5.0.)

Fire and health regulations pose special problems in the development of special dementia program and units in nursing homes. For example, fire safety regulations suitable for workers in an office building may fail to meet the needs of dementia patients, who may move slowly, who become easily confused or obstinate during an emergency, and who cannot follow instructions. Conversely, regulations may prohibit half doors to confine agitated patients, locked exists, or other features used to manage patients' behaviour. Public health regulations also may create programming problems. For example, plastic utensils may be required for sanitary reasons but may confuse residents by their unfamiliar weight and size (OTA 1988).

The National Institute on Adult Daycare in the United States (a constituent unit of the National Council on Aging) has developed voluntary standards and guidelines for good practice, to serve as ideals guiding program development (National Institute on Adult Daycare, 1984). Key aspects of the guidelines are presented below.

o Staffing

The recommended staff-participant ratio is 1:8 generally, but 1:5 in programs with a high percentage of severely impaired participants. Volunteers may be included in the staff ratio only if they meet the same standards as paid staff. All staff and volunteers should receive regular in-service training. General qualifications and responsibilities for 11 staff positions are also presented; the director, for example, should preferably be a professional with a degree in health or human services or a related field and essential experience to ensure that services are provided appropriately.

o Services

Essential components are an individual plan of care and various services. The plan of care includes an individual assessment, plan of service, progress notes, reassessment at least semi-annually, and a discharge plan. Essential services are personal care; social, leisure, physical and educational activities; health monitoring; nutrition; transportation if possible; emergency services, including emergency information for each participant; individual and group counselling for families and participants; and maintenance of relationships with the community through advocacy, information and referrals, and co-ordination of service.

o Activities

General guidelines are presented for the planning, scope and schedule of activities, recommending activities be planned by staff in co-ordination with participants, families, caregivers, volunteers and other interested parties.

o Program evaluation

A plan for evaluation should be prepared and implemented at least annually, with input from the governing body, the program director and staff, participants and their families, and outside agencies.

o Facility

The facility should be designed to accommodate disabled individuals and must meet any state and local barrier-free requirements. Preferably, the facility should be at street level. At least 40 square feet of space should be provided for each participant, excluding hallways, rest rooms, offices and storage areas. At least one toilet, equipped for use by a mobility limited person, should be provided for every 10 participants. The facility should include a rest area, an isolation area for participants who become ill, space for special therapies, lockers or other provision for participants' possessions, and outdoor space.

7.0 KEY INFORMANTS: OBSERVATIONS ON CANADIAN PROGRAMS OUTSIDE ONTARIO

As a supplement to the literature about Canadian programs available to persons with dementias and their caregivers, key informants[1] (Appendix B) were identified in areas outside Ontario and were interviewed by telephone. Information was requested on:

- number of programs by type;
- funder/sponsor of the various programs;
- program status;
- key component/features of each type of program;
- the most effective types of programs;
- identifiable community prerequisites;
- key issues/problems;
- future trends in programming and care; and
- guidelines, standards, legislation, etc.

While all informants were generally knowledgeable regarding long-term care programs and programs for the cognitively impaired (in provinces where such programs have been developed), most lacked specific knowledge as to number of programs available, types of services available within each program, etc. In many instances, informants were unsure as to whether cognitively impaired seniors were accepted by other long-term care programs. Information provided on each jurisdiction reflects the opinions of the respondents. Relevant documents and reports were requested and, if provided, were reviewed.

Only in Saskatchewan were key informants aware of provincial dollars targeted specifically toward programs for cognitively impaired elderly persons, although some provincially-funded programs in British Columbia, Alberta, Manitoba, and Quebec serve this population either specifically or predominantly.

Key informants in the other provinces and the territories mentioned programs that were open to all elderly persons at risk of institutionalization. For example, in-home support or home care programs -- usually including nursing, homemaking, home repairs essential to independence of the client, and meal preparation but sometimes also personal care, occupational and physical therapy and transportation -- are available (or are being developed) in every province and territory. Eligibility criteria vary and some provinces (e.g.

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1 Most key informants for this review are provincial representatives of the newly formed Federal/Provincial Steering Group on Psychogeriatric Services.

Newfoundland) require income testing of the client and caregiver. User charges are levied in some provinces; in Alberta's coordinated home care program, for example, users are not directly charged for health or personal care services but pay $2/h or $2/meal (to a maximum $300 monthly) for other supports. In Saskatchewan, there are no direct charges for nursing services but, for meals, homemaking and home maintenance, a user charge is based on income and the number of units of service received in a month. One unit is one meal or one hour of service, and all users -- regardless of income -- pay $5/unit for the first ten units. In Manitoba, there are direct costs to users, but they cannot exceed the cost for care in a personal care home (nursing homes) or other long-term care setting, and there is no time limit for service provision within these guidelines.

7.1 British Columbia

In British Columbia, key informants noted that funding for community-based care of patients with dementias comes from the general coffers for health and social services. Nevertheless, they said that in practice, the dollar rate at which the Ministry of Health funds participation by seniors with cognitive impairments is higher than that for other seniors since the funding is determined by the level of care a patient needs, according to an outside assessment. The amounts are calculated on a per-person, per-day basis.

A few community care facilities serve a large complement of patients with dementias and have changed the physical design to accommodate the special needs of such patients. Similarly, a few day programs have a concentration of cognitively impaired elderly participants, but according to key informants, none is regarded as a model for innovative programs.

Initiatives from the private sector indicate that interest is not limited to government. The British Columbia Long Term Care Association, in particular, has suggested changes and outlined how services should be developed to serve the public better.

Based on an assessment at one of five short-term assessment and treatment centres in urban areas of the province, the Continuing Care Division within the Ministry of Health funds a large variety of services (Exhibits 7.1 and 7.2). Although the assessment centres are all purpose, the referrals are mainly for depressed or cognitively impaired persons. Five levels of care are covered by the Division:

- Personal (non-professional supervision or assistance);
- Intermediate 1 (moderate assistance with activities of daily living and some professional care);

- Intermediate 2 (heavier care or supervision over extended period);
- Intermediate 3 (usually for individuals experiencing severe behavioural problems on a continuing basis);
- Extended (24-h professional nursing services and medical supervision).

Exhibit 7.1 Number of Agencies and Clients Receiving Institutional Services (British Columbia, Ministry of Health 1986)

Type of Institution	Number of Institutions	Number of Clients
Personal and Intermediate Care Facilities	257	19,788
Hospitals	9	120
Private Hospitals	37	2,881
Family Care Homes	90	195

Exhibit 7.2 Number of Agencies and Clients Receiving Community Services (British Columbia, Ministry of Health 1986)

Community Service	Number of Agencies	Number of Clients
Homemakers	130	40,884
Adult Day Care	46	4,357
Group Homes	17	210
Home Nursing Care	81	32,466
Community PT and OT	49	7,047

A clinic at the University of British Columbia, under the direction of Dr. Lynn Beattie, is devoted to diagnostic assessment of patients suspected of having Alzheimer's disease. The clinic also undertakes some community liaison work but is not involved in any intensive follow-up.

The Alzheimer Society, with 27 chapters in the province, takes on the role of supporting and educating families. A provincially funded Geriatric Psychiatric Outreach Program is offering continuing medical education on case management and counselling. In this program, case consultation is used as a teaching tool for physicians in small communities.

7.2 Alberta

In Alberta, the responsibility for providing community and institutional programs and services is shared between the Ministry of Community and Occupational Health and the Ministry of Hospitals and Medical Care. The former funds the home care program, community health clinics, some adult day care and respite services, day hospitals and three long-term care centres. The latter funds nursing homes, auxiliary hospitals, and day hospitals as well as medicare.

The Ministry of Community and Occupational Health awards grants to agencies providing respite care programs and psychogeriatric day programs. In future, provincial funding is expected to be available for day programs specifically for persons with dementia in Calgary and Edmonton. Key informants mentioned, however, that rural programs are unlikely since such programs are seldom used to capacity. The Alzheimer Society of Calgary has recently submitted a proposal to the Ministry for funding of a day program.

Current day care programs for disabled and frail seniors cost the province $22/day for each participant, and users pay $3 daily.

The Ministry of Community and Occupational Health also funds three long-term care centres that provide psychogeriatric, chronic care, and respite services to residents in southern Alberta; one -- Rosehaven Home in Camrose -- will presently reduce the number of long-term care beds to 100, provide 100 short-term care beds and outreach services to a further 100 seniors on the day program, at their home or in the home of a family member.

Also, the Ministry of Hospitals and Medical Care is funding a pilot project specifically for patients with Alzheimer's disease. Undertaken by the Beverly Nursing Home in Calgary, the project is the first of its kind in Canada, according to David Martin, the executive director. The Centre will comprise 130 beds (10 for respite care, 120 for long-term care) of which 40 can serve adult day care. The plan is to have ten small households serving 13 seniors with Alzheimer's disease and related disorders. The physical environment will be planned according to the latest research on design for the cognitively impaired. Each household will have dining facilities and an activity area. Residents in each will have similar levels of cognitive

functioning and will be served by a specific group of staff members -- i.e., the staff will not rotate from one home to another and will remain with the same residents over time.

7.3 Saskatchewan

In Saskatchewan, the Continuing Care Division of the Ministry of Health is the primary public funder of services directed specifically to cognitively impaired elderly residents. At present, it supports 13 Behaviour Management projects in eight special care homes (homes for the aged) and regional care centres (nursing homes and auxiliary hospitals). The projects offer three main types of services: in-home support; assessment and consultation; and day care programs (Exhibit 7.3).

The primary type is in-home services to assist individuals whose cognitive impairments are such that they cannot be integrated into regular activities of the homes or centres.

The second type is consultation services, which operate out of regional care centres and cater to special care homes, providing assessment, care plan development, management recommendations, training, follow-up and evaluation. Included in this type of project are discrete behaviour management units that provide short-term, in-house assessment.

Exhibit 7.3 Centres With Projects Funded by the Continuing Care Division, Saskatchewan

Location of Service	Type of Service
Lutheran Sunset Home, Saskatoon	Adult day centre and in-house services
Regional Pioneer Village, Saskatoon	Adult day centre and consulting services (outreach and onsite)
Herb Bassett Home, Prince Albert	Adult day program
Parkland Regional Care Centre, Melford	In-house services and outreach consulting services
Palliser Regional Care Centre, Swift Current	In-house services and outreach consulting services
Foyer D'Youville Special Care Home, Gravelbourg	In-house services
Battleford Regional Care Centre, Battleford	In-house services
Extendicare, Moosejaw	In-house services

The third type -- adult day centres -- provides specialized programs, personal care and a meal on a daily basis. The major emphasis is to give respite to family caregivers.

Users are charged $5.25 per day for participation in the centres and must pay transportation costs of $1 or $2 a trip.

Projects in some locations have been in operation since 1984, whereas behavioural management consulting projects started within the last year.

No formal guidelines or standards regulate the development of the services, but the philosophy of the Continuing Care Division is to promote care in the least restrictive environment.

Despite these initiatives, key informants maintain that programs for cognitively impaired seniors are grossly underdeveloped in the province, being spread over several jurisdictions. They indicated that most caregivers advocate the development of community-based services through special care homes (homes for the aged) rather than institutionalization in nursing homes.

7.4 Manitoba

The Continuing Care Program in Manitoba is a provincial coordinating body for community care services. It has formal links with other health care sectors such as hospital and personal care homes. Case coordinators within the program assess clients' eligibility for benefits, facilitating comprehensive assessments, developing and coordinating care plans and initiating, authorizing or coordinating resources to implement the plan.

Although no funds have been set aside specifically for improving care of cognitively impaired elderly, key informants report that the 114 personal care homes licensed under the Manitoba Health Services Commission have ever-increasing numbers of such patients and are establishing -- with the assistance of the Long Term Care Programs Division of the provincial government -- special care units.

Many of the personal care homes offer adult day programs to provide respite for caregivers. The first provincially funded day program was opened in 1979 "to provide psychosocial programs in a supportive environment, provide relief to caregivers and to prevent premature institutionalization." Program guidelines were developed in 1985 and serve as an evaluative tool. As of spring 1987, 58 day programs were serving a total 949 day participants.

One mental health day program, supported by the Community Mental Health Program within the Ministry of Health, accepts elderly clients regularly. Located in Winnipeg, the program is not equipped to deal adequately with psychogeriatric problems, according to key informants.

7.5 Quebec

The administration of health and social services in Quebec is under the control of the Ministry of Health and Social Services. Establishments dealing with health and social services belong to one of the following four categories: hospital centres (centres hospitaliers -- CH); centres for social services (centres de services sociaux -- CSS); group homes (centres d'accueil -- CA); and local centres of community services (centres locaux de services communautaires-- CLSC). CLSCs play an important role at the regional level. They are supposed to constitute a bridge between the public and more specialized establishments -- the CSSs, CHs and CAs. Staff in CLSCs work in teams, typically including a family physician, a nurse, a social worker, a psychologist and a dietician. CLSCs tend to do more prevention work than most other health establishments, cooperating with other community organizations and agencies to implement various programs in health education. Their boards of directors normally include a relatively large number of users.

The Ministry favours an integrated approach with respect to servicing the population of the province, so there is little developed specifically for different target populations. Nevertheless a few group homes have set up what is called "specific units" for individuals with Alzheimer's disease. These are the result of individual initiatives and have not been encouraged by the Ministry. Next fall, the Ministry will set up a committee to study these initiatives, comparing the costs and benefits with the costs and benefits of the integrated approach.

Legislation passed a few years ago in the province includes an "individualized service plan," which health establishments are obliged to use to evaluate the needs of each person requesting health or social services. The "plan" delineates steps that the establishments follow to determine individual objectives and to reassess the client's needs after completion of prescribed services. This plan, which was developed by the Ministry (CTMSP -- classification par titres en milieu de soins et services prolongés), is now used by all staff in existing health establishments to evaluate the needs of their clientele and to determine the level and type of care. Previously, each CLSC, group home, etc. had its own criteria, and the level of service varied widely from one region to the other.

For all persons who seek assistance -- including seniors with dementia and their caregivers-- the first step toward receiving services is a visit to the local CLSC, where staff, with the help of other health establishments, if necessary, determine the level of service required. If they deem that the person can stay within the community, they arrange for care of the person at a day centre (centre de jour) or day hospital (hôpital de jour). As elsewhere, day hospitals are more specialized than day centres, serving mainly to obviate the need for inpatient care or to follow-up elderly patients recently released from hospital. Day centres have more of a social function. Often day hospitals are attached to acute-care hospitals or to CLSCs, and day centres, though usually attached to group homes, may be attached to CLSCs.

8.0 DEMENTIA PROGRAMS AND RESPITE PROGRAMS IN ONTARIO

8.1 Publicly Funded Programs

In the two years since the Ministry of Community and Social Services began funding programs for persons with Alzheimer's disease and related dementias, the allocations have doubled to about $4 million to cover operating costs of such programs and $600,000 for capital expenditures. A survey of 94 of the programs receiving support from MCSS is under way and will be reported separately. This section takes a look at what else is available in the province, which is fairly limited in the public sphere, comprising a number of nonspecific programs funded by the Ministry of Health.

No agency other than MCSS in the provincial government has programs directed specifically to aid individuals with Alzheimer's disease and related dementias. The Ministry of Health has no programs targetted towards Alzheimer's disease, although nursing homes under its jurisdiction are developing special units. The Ministry is currently assessing the situation and is defining a complementary initiative.

The Ministry of Health, through its Community Mental Health Branch, funds programs for individuals with psychiatric disabilities and cognitive impairments. Presumably, some people with Alzheimer's disease and related disorders benefit from these programs, a limited number of which are senior day and support programs. A directory is currently in production and is expected to be available for distribution before the end of the summer.

The Ministry's focus, however, is chronic care within institutions; thus, senior day programs and counselling programs are largely the result of initiatives by individuals, with the Ministry covering 100 per cent of operating expenses through transfer payments. Examples in Toronto are an outreach program at Sunnybrook Medical Centre through the regional geriatric unit; a program run by the Queen Elizabeth Hospital to treat elderly individuals abusing alcohol or other drugs; and a consulting program at West Park Hospital for other service providers who are dealing with the cognitively impaired.

Similarly, the Institutional Operations Branch of the Ministry of Health serves some elderly patients with Alzheimer's disease, in its geriatric day hospital program. The program does not focus on Alzheimer's patients, but they may be included in it because of an injury or other illness. The program is intended to provide physical rehabilitation for the elderly, with treatment available for six months.

The Ministry of Health also funds geriatric assessment units and psycho-geriatric programs. Geriatric assessment units, funded through hospital budgets, are found in most major teaching hospitals. Many patients assessed at the units have mental health problems or cognitive deficits. The Ministry funds 18 psychogeriatric programs, including two specializing in Alzheimer's disease. The Education and Family Support Program operated by the Alzheimer Society of Durham Region develops educational materials, provides educational programs to families and health care professionals, and works to alleviate the stress experienced by people who live and work with Alzheimer's disease. The Alzheimer Home Assistance Program operated by the Alzheimer society in Ottawa develops individual rehabilitation plans to optimize clients' functional competence in their homes. Plans are based on functional, psycho-social and family burden assessments, and are prepared in consultation with other service providers and family members.

The other psychogeriatric programs vary in terms of services offered, but most provide psychiatric and social assessments, often in the patients' home, plus treatment, referrals to other services and follow-up. Many offer information and education to families, the general public and other professionals. Some participate in the training of medical personnel, and advise hospitals and long-term care institutions on behaviour management strategies and other aspects of patient care.

The legislation governing the programs delivered by the Ministry of Health includes the Mental Health Act, which deals primarily with institutions; the Health Insurance Act, which defines the health programs supported provincially; and the Public Hospitals Act, which covers virtually all inpatient and outpatient programs offered on hospital premises.

No register of in-home, respite and senior day programs is available for the province but some local and district groups have put together directories for their areas. At present, the registry sub-committee of the Metropolitan Toronto Respite Care Coordination Committee is planning a survey, based on a questionnaire, and is currently submitting proposals for funding the project. The committee, which is made up of volunteers -- nurses, occupational therapists, social workers, and members of the provincial and municipal government -- is anticipating a time frame of six months.

A directory was recently compiled by the Ottawa-Carleton Regional District Health Council (1988); it includes phone numbers for agencies -- public, non-profit and profit-seeking. It also includes some questions for consumers to ask when contacting private-pay agencies.

8.2 Private Pay Programs

In-home nursing care is widely available for respite for those who can afford to pay, as is clear from the lists of nursing service agencies within the yellow pages of telephone directories. Besides nursing, services include hairdressing, homemaking, transport, meal preparation and home repairs that are set up by both profit and non-profit agencies. Less easy to find are beds set aside for short-stay respite services, although a few agencies do have them. Agencies will send a nurse to an individual's home to discuss requirements and a plan for care. Administrators of the agencies acknowledge that some of the consumers are families of Alzheimer's patients, although the volume is less clear. Several agencies advertise as specializing in care of the elderly and patients with dementias. The burgeoning of services and the study team's research indicate the market is considerable.

8.3 Guidelines and Standards for Senior Day and Respite Programs in Ontario

To date, no guidelines or standards have been designed specifically for senior day programs and respite programs serving individuals with Alzheimer's disease or related disorders in Ontario. The guidelines developed for senior day programs under the auspices of MCSS outline essential components of services for elderly people at risk of institutionalization. Although the guidelines were originally intended to be used by programs serving patients with cognitive or psychosocial impairment as well as those with physical disabilities, a survey in 1985 indicated that the programs seldom included participants with moderate or severe deficits. The guidelines, though applicable, were clearly not sufficient.

Similarly, general principles for establishing and administering respite programs have been assembled by a joint committee of MCSS and the Ontario Association of Family Respite Services: Guidelines for Family Respite Programs. These were published in March 1987 and are available from the Ontario Government Bookstore. The guide defines concepts in community-based respite services -- short-term relief for caregivers -- that enable elderly persons to remain in their homes in the community. Host families, in-home visits and special facilities are considered suitable delivery models for all respite services but the particular requirements of programs directed to people caring for individuals with dementias have not yet been given attention.

Early this year, the federal government published Guidelines for Comprehensive Services to Elderly Persons with Psychiatric Disorders. Prepared by the Mental Health Division (Canada, Health and Welfare 1988b), "it does not provide a detailed blueprint or standard for service planning and delivery, nor was it intended to; rather, it identifies mechanisms and outlines

principles that can be applied in accordance with the...needs, structures and circumstances of different regions." It touches on the assessment, management and treatment options, coordination of services and resources, roles and needs of volunteers and voluntary agencies.

Other guidelines published by Health and Welfare (1979a,b; 1984a, 1986, 1988a) do not deal specifically with programs for the elderly with dementias, although a few -- for stroke programs, adult psychiatric services, adult long-term institutional care and geriatric day hospitals and units -- are peripherally related.

A publication from the Ontario Association of Homes for the Aged (1985) deals with care of functionally impaired elderly persons. Initially entitled "Does It Really Matter If It's Tuesday", the Guide for Caring for Mentally Impaired Elderly is directed toward institutional requirements more than community-based care. Much the same can be said about Institutional Care of the Mentally Impaired Elderly by Singer Edelson and Lyons (1985).

A publication outlining principles in the physical environment for patients with dementia is available (Calkins 1988) and a few documents deal with legal issues in the care of mentally impaired seniors in Ontario (Alzheimer Society for Metropolitan Toronto 1987; Working Group on Legal Issues 1987).

In 1985, a Task Force on Day Programs for the Confused Elderly (Ontario, Metropolitan Toronto District Health Council 1986) surveyed agencies and institutions offering senior day programs in Toronto. Only two programs had been specifically set up for the confused. No standards existed and "Almost without exception, the aggressive, incontinent or wandering client was excluded...." With the funds that have since been made available by MCSS, the numbers of programs have increased, but little has changed in the availability of standards.

Lobbying for improvements is one of the focuses of the Alzheimer Society of Canada, which "has been spearheading public discussion across the country and developing proposals for a more appropriate legal framework" (Working Group on Legal Issues 1987).

8.4 Structure and Role of Alzheimer's Societies in Ontario

The national office of the Alzheimer Society of Canada exists mainly to lobby the federal government on issues that bear on Alzheimer's patients and their caregivers. It also carries out an awareness program that includes publishing and publication distribution. Other activities

include coordinating national action by its affiliated provincial and local chapters as well as collecting monies and awarding grants to Canadian researchers.

Where they exist, the provincial level societies lobby provincial government, assist in the establishment of new chapters, collect data on members, and assist with fundraising. In Ontario, the provincial association works closely with government and has benefitted from funding for example through the Trillium program. Currently, it is affiliated with 29 chapters (Appendix C), the majority of which have become incorporated, and the number is growing rapidly.

Local chapters -- the city or community associations -- are the essence of the society. They are autonomous, setting their own goals and priorities. To become affiliated with the national and provincial offices, they must have at least five officers. The members decide whether they will undertake programs directly or promote program delivery by other agencies. Many chapters currently are operating senior day programs for Alzheimer's patients; organizing seminars and support groups; and offering emergency respite as well as counselling services.

A look at the Ottawa chapter provides some indication of what is happening at the local level. With 600 members, it is one of the largest chapters in Ontario. According to its executive director, Kathy Wright, the main thrusts of its work are to provide support to families of Alzheimer's sufferers and to lobby or act as advocates for its members, although secondary goals are fundraising, promoting research and undertaking education.

With a 14-member board, the chapter has standing committees on education; fundraising; public relations and advocacy; family support; programs; and nominations. The executive comprises a president, past-president, vice-president, secretary-treasurer, one member at large, and the executive director as an ex-officio member. Each board member is also a member of one of the committees, which meet monthly. Annually, all the committees meet to set strategies for the coming year.

The chapter employs two family support workers -- one to work with senior day program and home care program managers and the other to act as a first contact for inquiries about Alzheimer's disease and related matters. The latter does some counselling but mainly shares information, asks questions about the behaviour of the family member suspected of Alzheimer's disease, etc.

The office is building a resource centre, including videocassettes for rent or viewing at the office and relevant books available on loan, and the education committee is setting up a

speakers' bureau. These activities are relatively new and are in response to a marketing study by the University of Ottawa showing a general lack of awareness on the part of the public.

Currently, the chapter also operates two "day away" programs, although two years ago the board of directors decided to concentrate on activities other than program delivery and to divest itself of current programs. The rationale was that service delivery could consume all the resources of the chapter and that promoting, and advising on, such programs would ensure their availability while leaving chapter members and staff free for other work.

APPENDIX A

PROCEDURES USED FOR CONDUCTING THE LITERATURE SEARCH

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PROCEDURES USED FOR CONDUCTING THE LITERATURE SEARCH

Computerized literature searches were conducted as a first step in identifying appropriate background literature, programs, and contact persons. Approximately 200 references were retrieved from 14 different online databases. These references were reviewed by the study team and approximately 60 were selected for further exploration. Since the online databases only provide references and short summaries of the source documents, copies of the selected documents were obtained from libraries throughout Ontario.

SEARCH STRATEGY

The databases were searched for any items dealing with Alzheimer's Disease or Senile Dementia together with Caregivers or Social Support Groups or Daycare or Respite Care. The actual search strategy used for each database varied somewhat depending on the content and indexing vocabulary of the particular database.

Other references were obtained from reference lists in articles identified in the database search and from suggestions from key informants.

DATABASES SEARCHED

The databases searched via the DIALOG information retrieval system included:

1. ERIC (Educational Resources Information Centre, Syracuse, NY)
2. Health Planning and Administration (US National Library of Medicine)
3. MEDLINE (US National Library of Medicine)
4. Social Scisearch (Institute for Scientific Information, Philadelphia, PA)
5. Books in Print
6. PsychInfo (American Psychological Association)
7. Family Resources (US National Council on Family Relations)
8. Government Publications Office Monthly Catalogue (US)
9. Public Affairs Information Service
10. Magazine Index
11. Canadian Business and Current Affairs

Databases searched via the BRS system included:

12. AGELINE (American Association of Retired Persons)

Databases searched via InfoGlobe included:

13. Globe & Mail Online
14. Canadian Periodical Index

THE SEARCH RESULTS

Computerized databases contain primarily listings of journal articles and books. There are no databases that specifically list social programs; information about programs is found via online databases only if someone has written an article or perhaps a book chapter about a program and submitted it to a professional journal or edited book.

Some newspaper and magazine indexes were searched and these identified stories about programs based on staff and client interviews. Individuals listed as authors in the bibliographic databases and the names listed in newspaper and magazine stories were sought as potential key informants for the study. A special effort was made to search Canadian databases and to watch for Canadian references in U.S. databases.

Computerized searching has provided a rapid and comprehensive view of the current literature related to the care of persons with dementias. Since it is usually the leaders in the field who are published in the professional literature, the search has provided the project with a "state-of-the-art" view of research and other activities.

The bibliography contains all references cited in the report plus others that could not be reviewed within the time frame of the study or could not be obtained.

APPENDIX B

LIST OF KEY INFORMANTS

APPENDIX B

LIST OF KEY INFORMANTS

Name	Location	Affiliation	Position
Dan Andreae	Toronto	Alzheimer Society of Metro Toronto	President
Douglas W. Archibald	Halifax	Department of Public Health	Administrator, Psychiatric Mental Health Services
Margaret Barbour	Winnipeg	Continuing Care Program, Manitoba Health	Program Administrator
Dennis Barr	Edmonton	Mental Health Services	Associate Director
Bill Bell	Regina	Continuing Care Branch	
Lois Borden	Regina	Home Care Programs	Director
Verna Bruce	Charlottetown	Department of Health & Social Services	Home Care and Support
Noreen Conley	Charlottetown	Department of Health & Social Services	Division of Aging and and Extended Care
John Crawford	Saskatoon	University of Saskatoon	Researcher
Alan Davidson	Yukon	Department of Health and Human Resources	Director, Health Services Branch
Leota Embleton	Toronto	Department of Social Work, The Queen Elizabeth Hospital	Chairman of Task Force on Programs for the Confused Elderly
Sandra Flagler	Toronto	Ontario Association of Non-Profit Homes and Services For Seniors	Director of Membership Services
Joyce Flieser	Toronto	Alzheimer Society of Metro Toronto	Vice-Chair, Metropolitan Toronto Respite Care Coordination Committee
Adele Furrie	Ottawa	Health and Activity Limitation Survey, Statistics Canada	Program Manager, Disability Database
Eckhard Goerz	Winnipeg	Office of Continuing Care, Manitoba Health	Program Specialist, Social Work
Donna Gordon	Fredericton	Department of Health & Community Services	Mental Health Services
Dory Gould		Alzheimer Society of Canada	Office Manager

John Gray	Victoria	Mental Health Services, and Federal/Provincial Steering Group on Psychogeriatric Services	Director, Services to Elderly, and Member
Joan Harvey	Ottawa	Senior's Secretariat, Health and Welfare Canada	Environmental Psychologist, Consultant
E. Helmes, Ph.D	London	Dept. of Psychiatry University of Western Ont. London Psychiatric Hospital	Professor, Psychologist
Marcus Hollander	Victoria	Ministry of Health	Director, Program and Management Analysis, Continuing Care Division
Kathy Kinchen	Yukon	Department of Health and Human Resources	Director, Human Resources
Andrew Langford	Yellowknife	Alcohol, Drug and Community Mental Health	Director
Pierre LeBlanc	Fredericton	Nursing Home Services	Assistant Director
Joan Linsey	Ottawa	Laboratory Centre for Disease Control, Health and Welfare Canada	Epidemiologist
Thomas Lips	Ottawa	Mental Health Division, Health and Welfare Canada	Coordinator, Guidelines Committee
James MacIsaac	Halifax	Department of Social Services	Administrator, Rehabilitation & Community Services
Gordon MacKay	Charlottetown	Department of Health and Social Sciences	Director, Division of Aging and Extended Care
Roy Manuel	St. John's	Department of Health	Nursing Consultant
Margaret Marshall	Yellowknife	Department of Health	
Anne Martin Mathews	Guelph	University of Guelph	Director, Gerontology Research Centre
David Martin	Calgary	Beverly Nursing Home	Executive Director
Julianne Martyniuk	Toronto	Institutional Operations Branch, Ministry of Health	Senior Administration Consultant
Loretta Mathieson	Toronto	Ministry of Health	Policy Coordinator Nursing Home Branch
Debi Mauro	Toronto	Ministry of Health	Director, Community Mental Health Branch

J.J. McCall	Vancouver		Freelance Writer and Broadcaster
D.F. McLean	Winnipeg	Mental Health Services	Assistant Deputy Minister
Ellen Milnes	Toronto	Victorian Order of Nurses in Ontario	Executive Director
Ann Mohide	Hamilton	McMaster University	Faculty of Nursing
Michelle Moreau	Quebec City	Ministry of Health and Social Services	Programme pour personnes agées en perte d'autonomie
Betty Nicolson	Toronto	Ministry of Health	Senior Consultant, Home Care Programs
Mark Novak	Winnipeg	University of Manitoba	Sociologist
Dennis Ostercamp	Edmonton	Mental Health Services	
Irma Parhad	Calgary	University of Calgary	Researcher, Clinician, Department of Pathology
Cathy Park	Toronto	Metropolitan Toronto District Health Council	
Steve Petz	Regina	Continuing Care Branch	Executive Director
Marg Redston	Winnipeg	Manitoba Health Services Commission	
Rhoda Regenstreif	Edmonton	Alberta Community and Occupational Health	Coordinator, Long Term Care Planning
Rosemary Seaman	Yukon	Department of Health and Human Resources	Policy Analyst, Health Services Branch
Ken Shulman	Toronto	Sunnybrook Medical Centre	Psychiatrist
Arnold Skulmoski	Victoria	Mental Health Services	Social Worker
Marian Sinclair	Yukon	Department of Health and Human Resources	Health Services Branch
Leroy Stone	Ottawa	Statistics Canada	Director, Population Studies Division
Mary Tierney	Toronto	Sunnybrook Hospital	Psychologist/Researcher
Maxine Topley	Winnipeg	Manitoba Health	Program Specialist, Mental Health Directorate
Kathy Turner	St. John's	Department of Health	Gerontological Nurse Specialist

Claude Voisine	Quebec	Ministère de la santé, Province de Québec	Direction de la santé mentale
Kathy Wright	Ottawa	Alzheimer Society of Ottawa-Carleton	Executive Director
John Yarske	Regina	Mental Health Services	Executive Director

APPENDIX C

ONTARIO CHAPTERS OF THE ALZHEIMER SOCIETY OF CANADA

APPENDIX C

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BIBLIOGRAPHY

Alzheimer Society of Canada. 1987. Alzheimer's Disease: A Family Handbook. Toronto: Alzheimer Society of Canada. 22pp.

Alzheimer's Society for Metropolitan Toronto. 1987. Alzheimer's Disease -- Legal and Financial Concerns. Toronto: Alzheimer Society.

Aronson, Miriam K., Levin, Gilbert and Lipkowitz, R. 1984. "A Community-Based Family/Patient Group Program for Alzheimer's Disease." Gerontologist. vol. 24(4), Aug. , pp.#339-342.

Bader, J.E. 1985. "Respite Care: Temporary Relief for Caregivers." Women Health, vol. 10#(2-3), Summer-Fall, pp.#2-3, 39-52.

Barnes et al. 1981. "Problems of Families Caring for Alzheimer Patients: Use of a Support Group." Journal of the American Geriatrics Society, vol. 29(2), Feb., pp.#80-85.

Bergmann, K. 1985. "Epidemiological Aspects of Dementia and Considerations in Planning Services." Danish Medical Bulletin Gerontology Special Supplement Series vol. 32(1) February 84-91.

Bondareff, William. 1986. "Biomedical Perspective of Alzheimer's Disease and Dementia in the Elderly," in Gilhooly, Zarit and Birren, editors.

British Columbia, Ministry of Health. 1986. "Continuing Care Division Annual Report, 1985/86". Victoria: Ministry of Health.

Calkins. Margaret. 1988. Design for Dementia. Owing Mill, MD: National Health Publishing Company.

Canada. Health and Welfare. 1979a. Adult Psychiatric Services Provided by General Hospital Guidelines. Ottawa: Ministry of Supply and Services, 33pp.

Canada. Health and Welfare. 1979b. Geriatric Units in Hospitals - Geriatric Day Hospital Guidelines. Ottawa: Health and Welfare Canada, 24pp.

Canada. Health and Welfare. 1984a. Adult Long Term Institutional Care. Ottawa: Health and Welfare Canada, 128pp.

Canada. Health and Welfare. 1984b. Alzheimer's Disease. A Family Information Handbook. Mental Health Division, Health Services and Promotion Branch.

Canada. Health and Welfare. 1986. Stroke Program Guidelines. Ottawa: Health and Welfare Canada, 18pp.

Canada. Health and Welfare. 1988a. Elements of the Seniors Initiative. Ottawa: Health and Welfare Canada, 14pp.

Canada. Health and Welfare. 1988b. Guidelines for Comprehensive Services to Elderly Persons with Psychiatric Disorders. Ottawa: Health and Welfare Canada, 34pp.

Canada. National Advisory Council on Aging. 1984. Coping and Helping with Alzheimer's Disease. Ottawa: Ministry of Supply and Services.

Canada. Statistics Canada. 1987. A National Database on Disabled Persons. Ottawa: Statistics Canada, 19pp. plus appendices.

Caranasos, G.J., et al. 1985. "Caregivers of the Demented Elderly." Journal of the Florida Medical Association., vol. 72(4), April, pp. 266-270.

Carey, Betsy and Hansen, Shannon. 1986. "Social Work Groups with Institutionalized Alzheimer's Disease Victims." Journal of Gerontological Social Work, vol. 9(2), pp.#15-25.

Caserta, M.S., et al. 1987. "Caregivers to Dementia Patients: The Utilization of Community Services." Gerontologist, vol. 27(2), April, pp.#209-214.

Cheek, Leane B. 1987. "Easing the Burden on Alzheimer's Families." Aging, no. 355, pp. 16-19.

Chenoweth, B. and Spencer, B. 1986. "Dementia: The Experience of Family Caregivers." Gerontologist, vol. 26(3), June, pp.#267-272.

Cicirelli, Victor. 1986. "Family Relationships and Care/Management of the Dementing Elderly," in Gilhooly, Zarit and Birren, editors.

Cohen, Donna. 1986. "Guest Editor's Perspective." Pride Institute Journal of Long Term Home Health Care, vol. 5(3), p 2.

Cohen, Donna and Eisdorfer, Carl. 1986. The Loss of Self. A Family Resource for Alzheimer's Disease and Related Disorders. New York: W.W. Norton.

Cohen, Gene D. 1984. "Treatment of Alzheimer's Disease and Related Disorders: Research, Practice and Policy. "in William Kelly, editor, Alzheimer's Disease and Related Disorders, Research and Management. Springfield, III.: Charles C. Thomas, Publisher.

Cole, Laura, Griffin, Karla and Ruiz, Barbara. 1986. "A Comprehensive Approach to Working with Families of Alzheimer's Patients." Journal of Gerontological Social Work, vol. 9(2), Winter, pp.#27-39.

Colerick, Elizabeth J., and George, Linda K. 1986. "Predictors of Institutionalization Among Caregivers of Patients with Alzheimer's Disease." Journal of the American Geriatrics Society, vol. 34(7), July, pp.#493-498.

Coons, Dorothy and Weaverdyck, Shelly. 1986. "Wesley Hall: A Residential Unit for Persons with Alzheimer's Disease and Related Disorders." Physicial and Occupational Therapy in Geriatrics, vol. 4(3), pp.#29-53.

Cox, Kim G. 1985. "Alzheimer's Disease: Milieu Therapy." Geriatric Nursing, vol. 6(3), May-June, pp.#152-154.

Crook, T. and Gershon, S. 1981. Strategies for the Development of an Effective Treatment for Senile Dementia. New Canaan, CN: Mark Pawley.

Cutler, Loraine. 1985. "Counseling Caregivers." Generations. vol. 10(1), Fall pp.#53-57.

Dastoor, D.P. and Cole, Martin. 1987. "The Course of Alzheimer's Disease: An Uncontrolled Longitudal Study". CAG/Acg Newsletter, vol. 15(1), pp.#8.

DCP (Developmental Consulting Program). 1985. Alzheimer's Disease - A Report Submitted to the Policy Development Branch, Ontario Ministry of Community and Support Services.

Dunn, R.B., MacBeath, L., and Robertson, D. 1983. "Respite Admissions and the Disabled Elderly." Journal of the American Geriatrics Society, vol. 31(10), pp.#613-616.

Dunn, Louise. 1986. "Senior Respite Care Program." Pride Institute Journal of Long Term Home Health Care, vol.5(3), Summer, pp.#7-12.

Ellis, V. and Wilson, D. 1983. "Respite Care in the Nursing Home Unit of a Veterans' Hospital." American Journal of Nursing, Oct.

Evalusearch Research Consultants. 1985. The Société Alzheimer Society of Ottawa-Hull Day Away/Home Assistance Programs Evaluation: Final Report. Preparef for the Ministry of Community and Social Services.

Fabisewski, Kathy J., and Howell, Mary C. 1985-1986. "A Model for Family Meetings in the Long Term Care of Alzheimer's Disease." Journal of Gerontological Social Work, vol. 9(2), Winter, pp.#113-117.

Ferris, Steven H., et al. 1987. "Institutionalization of Alzheimer's Disease Patients: Reducing Precipitating Factors Through Family Counseling." Home Health Care Services Quarterly, vol. 8(1), pp.#23-51.

Fisk, A.A. 1983. "Management of Alzheimer's Disease." Postgraduate Medicine, vol. 73(4), April, pp.#237-241.

Fisk, Albert A., and Pannill, Fitzhugh C. 1987. "Assessment and Care of the Community Dwelling Alzheimer's Disease Patient." American Geriatrics Society Journal, vol. 35(4), April 1, pp.#307-311.

Fitting, Melinda, et al. 1986. "Caregivers for Dementia Patients: A Comparison of Husbands and Wives." Gerontologist, vol. 26(3), June, pp.#248-252.

Fox, Mary V. 1986. Social and Psychological Distress Among Spouse Caregivers of Dementia Patients. Ph D Dissertation. Tucson, AR: University of Arizona, 114 pp.

French, Carolyn J. 1986. "Development of Special Services for Victims and Families Burdened by Alzheimer's Disease." Pride Institute Journal of Long Term Home Health Care, vol. 5(3), Summer, pp.#19-27.

Furrie, A. 1987. A National Database on Disabled Persons: Making Disability Data Available to Users. Ottawa: Statistics Canada.

Gates, K. and Marshall, L. 1987. "A Committee That Works." Gerontion, vol.2(1), Spring, pp.#8-10.

George, Linda K. and Gwyther, Lisa P. 1986. "Caregiver Well-Being: A Multidimensional Examination of Family Caregivers of Demented Adults." Gerontologist, vol. 26(3), June, pp.#253-259.

George, M.V. and J. Perrault. 1985. Population Projections for Canada, Provinces and Territories 1984-2006. Statistics Canada 1985. Catalogue 91-520.

Gilhooly, Mary; Zarit, Steven; and Birren, James, editors. 1986. The Dementias. Polict and Management. Englewood Cliffs, N.J.: Prentice-Hall, 227 pp.

Gilhooly, Mary L. 1986. "Senile Dementia: Factors Associated with Caregivers' Preference for Institutional Care." British Journal of Medical Psychology, vol. 59(2), June, pp.#165-171.

Gilleard, C.J., et al. 1982. "Problems in Caring for the Elderly Mentally Infirm at Home." Archives of Gerontology and Geriatrics, vol. 1(2), Sept. pp.#151-158.

Gilleard, C.J. 1985. "The Impact of Psychogeriatric Day Care on the Patient's Supporting Relatives." Health Bulletin. (Edinburgh), vol. 43(4), July, pp.#199-205.

Glosser, G. and Wexler, D. 1985. "Participants' Evaluation of Educational Support Groups for Families of Patients with Alzheimer's Disease and Other Dementias." Gerontologist, vol. 25(3), June, pp.#232-236.

Good, V. 1984. "Britain Care: Providing a Wide Range of Low Cost Services." Generations, vol. 9(2), Winter.

Gottlieb, Benjamin. 1987. "The Family Support Project - Feedback Report." College of Social Science, Department of Psychology. University of Guelph.

Grossman, Helene D. et al. 1986. "The Milieu Standard for Care of Dementia in a Nursing Home." Journal of Gerontological Social Work, vol. 9(2), pp.#73-89.

Gurland, Barry J. 1984. "Public Health Aspects of Alzheimer's Disease and Related Dementias." William Kelly, ed. Alzheimer's Disease and Related Disorders. Springfield III.: Charles C. Thomas, Publisher. pp.#146-158.

Gustafson, Lars. 1985. "Differential Diagnosis with Special Reference to Treatable Dementias and Pseudodementia Conditions." Danish Medical Bulletin, Gerontology Special Supplement Series, vol.32(1), February, pp.#55-59.

Gwyther, L. 1986. "Introduction: What is Respite Care?" Pride Institute Journal of Long Term Home Health Care, vol. 5(3), Summer, pp.#4-6.

Gwyther, L.P., and George, Linda K. 1986. "Caregivers for Dementia Patients: Complex Determinants of Well-Being and Burden." Gerontologist, vol. 26(3), June, pp.#245-247.

Haley, W.E., et al. 1987. "Psychological, Social and Health Consequences of Caring for a Relative with Senile Dementia." Journal of the American Geriatrics Society, vol. 35(5), May, pp.#405-411.

Haley William E., Brown, S. Lane, and Levine, Ellen G. 1987. "Experimental Evaluation of the Effectiveness of Group Intervention for Dementia Caregivers." Gerontologist, vol. 27(3), June, pp.#376-382.

Hall, Geri, et al. 1986. "Sheltered Freedom. An Alzheimer's Unit in an ICF." Geriatric Nursing, vol. 7(3), May-June, pp.#132-137

Hanley, Odette, and Peele, Kate. 1985. "An Active Occupational Therapy Programme for the Severely Demented Patient in a Psychogeriatric Day Hospital." British Journal of Occupational Therapy, vol. 48(11), Nov., pp.#336-338.

Hassinger, Marla. 1985. Community-Dwelling Dementia Patients Whose Relatives Sought Patient Care: Predictors of Institutionalization Over a One-Year Follow-Up Period. Pasadena: University of Southern California, Ph.D. Dissertation.

Hay, Joel and Ernst, Richard. 1987. "The Economic Costs of Alzheimer's Disease." American Journal of Public Health, vol. 77(9), Sept., pp.#1169-1175.

Henry, James P. 1986. "Relation of Psychosocial Factors to the Senile Dementias," in Gilhooly, Zarit and Birren, editors.

Heston, L.L. and White, J.A. 1983. Dementia -- A Practical Guide to Alzheimer Disease and Related Illness. New York: W.H. Freeman.

Hepburn, Kenneth and Wasow, Mona. 1986. "Support Groups for Family Caregivers of Dementia Victims: Questions, Directions and Future Research." New Directions for Mental Health Services, no. 29, March, pp.#83-92.

Hildebrandt, Eugenie. 1983. "Respite Care in the Home." American Journal of Nursing, Oct., pp.#1428-1431.

Hirst, Sandra P. and Metcalf, Barbara J. 1986. "Learning Needs of Caregivers." Journal of Gerontological Nursing, vol. 12(4), April., pp.#24-28.

Hollander, Marcus. 1988. "A Strategic Plan for the Application of Research to Policy Making and Program Development in Continuing Care in British Columbia". Paper presented at Connections '88: First International Symposium on Research and Public Policy on Aging and Health, Saskatoon, February 8-10.

Jeans, E.R., et al. 1987. "Some Calculations on the Prevalence of Dementia in Canada." Canadian Journal of Psychiatry, vol. 32(2), March, pp.#81-86.

Jenkins, Terry S. Parham, Iris and Jenkins, Larry. 1985. "Alzheimer's Disease: Caregivers' Perceptions of Burden." Journal of Applied Gerontology, vol. 4(2), Dec. 1985, pp.#40-57.

Kahan, Jason, et al, 1985. "Decreasing the Burden in Families Caring for a Relative with a Dementing Illness: A Controlled Study." Journal of the American Geriatrics Society, vol. 33(10), Oct., pp.#664-670.

Kelley, Frances A. 1986. "The Occupational Therapist's Role in Geropsychiatry Interdisciplinary Team Evaluation," Physical & Occupational Therapy in Geriatrics, vol. 4(3), Spring, pp.#81-94.

Keyes, B., and Szpak, G. 1983. "Day Care for Alzheimer's Disease: Profile of One Program." Postgraduate Medicine, vol. 73(4), April, pp.#245-250.

Kerwin, Patricia. 1985. "Adult Day Care: An Integrated Model." Journal of Gerontological Social Work, vol. 9(2), pp.#59-71.

Kramer, Joel. 1984. "Treating Families of Demented Patients: Two Group Models." Paper presented at Western Psychological Association. 64th Annual Meeting. Los Angeles: April 5-8, 13 p.

Kraus, Arthur S. 1984. "The Burden of Care for Families of Elderly Persons with Dementia." Canadian Journal on Aging, vol. 3(1), Spring, pp.#45-51.

LaBar, C. 1986. "Legislation Related to Alzheimer's Disease." Long Term Care Quarterly, vol. 1(2), Summer, pp.#32-39.

Lauter, Hans. 1985. "What Do We Know About Alzheimer's Disease Today?" Danish Medical Bulletin Gerontology Special Supplement Series, vol. 32(1), February, pp.#1-21.

Lawton, M. Powell; Fulcomer, Mark, and Kleban, Mortan H. 1984. "Architecture for the Mentally Impaired Elderly. Environment and Behaviour, vol. 16(6), November, pp.#730-757.

Macdonald, A.J., et al. 1982. "An Attempt to Determine the Impact of Four Types of Care Upon the Elderly in London by the Study of Matched Groups." Psychological Medicine, vol. 3(4), Fall, pp.#193-200.

Mace, N. 1984a. "Day Care for Demented Clients." Hospital & Community Psychiatry, vol. 35(10), Oct. pp.#979-980, 994.

Mace, N. 1984b. "Report of a Survey of Day Care Centres." Pride Institute Journal of Long Term Home Health Care, vol. 3(4), Fall, pp.#38-43.

Mace, Nancy. 1986. "Home and Community Services for Alzheimer's Disease". Physical and Occupational Therapy in Geriatrics, 4(3), Spring, pp.#5-13.

Mace, Nancy L. and Rabins, Peter V. 1981. The 36-Hour Day. A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life. New York: Warner Books.

Mac Fadgen, Lynn. 1987. "The Care of Irreversible Dementia Sufferers in the Toronto and Peel Regions: Perceptions of Service Providers." Canadian Journal on Aging, vol. 6(4), Winter, pp.#271-289.

Maiden, Robert J., et al. 1985. "Caregiving for Dementia in Family Members: Caregiving Burden and Prospects for Effective Intervention." Paper presented at Eastern Psychological Association. Annual Meeting. Boston: March 21-24, 11 p.

Maloney, Charlotte and Daily, Terran. 1986. "An Eclectic Group Program for Nursing Home Residents with Dementia." Physical and Occupational Therapy in Geriatrics, vol.4(3), pp.#55-79.

Manitoba, Health Services Commission. 1987. "Annual Report - 1986-87". Winnipeg: Manitoba Health Services Commission.

MSOS (Manitoba Society of Seniors). 1988. "Alzheimer's: Crisis in the Making." MSOS Journal, June, pp.#14-15.

Marco, Luis A. and Randels, Patricia M. 1984. "Neurobiology of Cognitive Deterioration." in William Kelly, editor, Alzheimer's Disease and Related Disorders, Research and Management. Springfield, III.: Charles C. Thomas, Publisher.

Middleton, Lillian, et al. 1987. The Impact of Alzheimer's In-Home Respite Care on Patients and Family Caregivers. Washington: Administration on Aging. U.S. Dept. of Health and Human Services, p.182 (GPO Item #4476-A-1).

Middleton, L. 1987. "Training Respite Workers for Alzheimer's Families." Aging, no.#256, pp.#24-26.

Miller, Dulcy B., Gulle, N. and McCue, F. 1986. "The Realities of Respite for Families, Clients and Sponsors." Gerontologist, vol. 26(5), Oct., pp.#467-470.

Mirosh, Dianne. 1988. "A New Vision for Long Term Care - Meeting the Need". Discussion Paper commissioned by the Alberta Government.

Mohide, Ann et al. 1988. "Measuring the Wellbeing of Family Caregivers Using the Time Trade-off Technique." In press, Journal of Chronic Diseases.

Morscheck, P. 1984. "Introduction: An Overview of Alzheimer's Disease and Long Term Care." Pride Institute Journal of Long Term Home Health Care, vol. 3(4), Fall, pp.#4-10.

Murphy, E. 1986. Dementia and Mental Illness in the Old -- A Practical Guide: Understanding the Problems -- How to Manage -- Surviving Yourself. London: Macmillan.

National Institute on Adult Daycare. 1984. Standards for Adult Day Care. Washington: The National Council on Aging, Inc. 52pp.

Newfoundland. 1987. "Long Term Care Services".

Neysmith, Sheila and Lewis, Avril. No date. "Evaluating an In-Home Respite Program".

Niederhehe, George and Frugé, Ernest. 1984. "Dementia and Family Dynamics: Clinical Research Issues." To be published in the Journal of Geriatric Psychiatry, vol. 17(1).

Nielsen. J. 1963. Geronto-psychiatric Period-Prevalence Investigation in a Geographically Delimited Population. Acta Psychiatry Scand 38:307-330.

Nusberg, Charlotte, with Mary Jo Gibson and Sheila Peace. 1984. Innovative Aging Programs Abroad, Implications for the United States. London: Greenwood Press.

O'Connor, Kathleen and Brothers, Joyce, eds. 1987. The Alzheimer's Caregiver: Strategies for Support. Seattle: Univ. of Washington Press, 122 pp.

Oliver, Rose and Bock, Frances A. 1987. Coping with Alzheimer's -- A Caregiver's Emotional Survival Guide. New York: Dodd, Mead.

Ontario Association of Homes for the Aged. 1985. Guide to Caring for the Mentally Impaired Elderly. Toronto: Ontario Association of Homes for the Aged, 175pp.

Ontario, Metropolitan Toronto District Health Council. 1986. Report on the Task Force on Day Programs for the Confused Elderly. Toronto: Metropolitan Toronto District Health Council, 37pp.

Ontario. Ministry of Community and Social Services. 1987. Guidelines for Family Respite Programs. Toronto: Government Book Store, 39pp.

Ontario. Ministry of Community and Social Services. No date. Guidelines for Senior Day Programs. Toronto: Ministry of Community and Social Services, 8pp.

Ory, Marcia G., et al. 1985. "Families Informal Supports and Alzheimer's Disease: Current Research and Future Agendas." Research on Aging, vol. 7(4), Dec., pp.#623-644.

Ottawa-Carleton Regional District Health Council. 1988. Directory of Respite Care Services. Ottawa: Ottawa-Carleton Regional District Health Council, February.

OTA (U.S. Office of Technology Assessment). 1988. Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias: Congressional Summary. Washington: Office of Technology Assessment, 79 p. (GPO Item #1070-M).

Panella, J.J., et al. 1984. "Day Care for Dementia Patients: An Analysis of a Four-Year Program." Journal of the American Geriatrics Society, vol. 32(12), Dec., pp.#883-886.

Panella, John. 1986. "Toileting Strategies in Day Care Programs for Dementia." Clinical Gerontologist, vol. 4(3), Feb., pp.#61-63.

Parhad, I.M. 1988. "Alzheimer Disease: Research and Public Policy." Paper presented at Connections '88: First International Symposium on Research and Public Policy on Aging and Health, Saskatoon, February 8-10.

Peppard, Nancy R. 1986. "Special Nursing Home Units for Residents with Primary Degenerative Dementia: Alzheimer's Disease." Journal of Gerontological Social Work, vol. 9(2), pp.#5-13.

Perdue, Joanne. 1984. "Respite Care for the Frail or Disabled Elderly. Pride Institute Journal of Long Term Home Health Care, vol. 3(4), Fall, pp.#31-37.

Petrie, W.M. 1985. "Alzheimer's Disease." Compr Therapy, vol. 11(7), July, pp.#38-43.

Pluckhan, M.L. 1986. "Alzheimer's Disease: Helping the Patient's Family." Nursing, vol. 16(11), Nov., pp.#63-64.

Pratt, Clara C., et al. 1987. "Burden, Coping and Health Status: A Comparison of Family Caregivers to Community Dwelling and Institutionalized Alzheimer's Patients." Journal of Gerontological Social Work, vol. 10(1-2), Jan., pp.#99-112.

Pratt, Clara C., et al. 1985. "Burden and Coping Strategies of Caregivers to Alzheimer's Patients." Family Relations: Journal of Applied Family & Child Studies, vol. 34(1), Jan., pp.#27-33.

Preston, George A. 1986. "Dementia in Elderly Adults: Prevalence and Institutionalization." Journal of Gerontology, vol. 41(2), March, pp.#261-267.

Prince Edward Island, Department of Health and Social Services. 1987. "Seventh Annual Report, 1986-1987". Charlottetown: Department of Health and Social Services.

Pringle, Dorothy. 1988. "Diffusion Across A Semi-permeable Membrane." Paper presented at Connections '88: First International Symposium on Research and Public Policy on Aging and Health, Saskatoon, February 8-10.

Rabinowitz, Ellen. 1986. "Day Care and Alzheimer's Disease: A Weekend Program in New York City." Physical and Occupational Therapy in Geriatrics, vol. 4(3), Spring, pp.#95-103.

Randels, Patricia. 1984. "Biological Correlates of Primary Degenerative Dementia." in William Kelly, editor, Alzheimer's Disease and Related Disorders, Research and Management. Springfield, Ill.: Charles C. Thomas, Publisher.

Read, Sharon and Hamlet, Elizabeth. 1987. "Caregiver Education and Support Group: A Hospital Based Experience." A Paper Written for Presentation at the Canadian Gerontology Association Conference, October 22-26, 1987, in Calgary, Alberta.

Reever, K.E. 1984. "Self-help Groups for Caregivers Coping with Alzheimer's Disease: The ACMA Model." Pride Institute Journal of Long Term Home Health Care, vol. 3(4), Fall, pp.#23-30.

Reifler, Burton. V. 1985-1986. "Training in Geriatric Mental Health: Two Innovative Outpatient Training Sites." Gerontology and Geriatrics Education, vol. 6(2), Winter, pp.#65-73.

Reisberg, Barry. 1987. "Dementia: A Systematic Approach to Identifying Alzheimer's." Update on Aging, Gerontology Institute of New Jersey, vol. 3(4), Fall, pp.#3-4.

Robertson, D., et al. 1983. "Prevalence of Dementia in the Elderly Population of Saskatchewan." Canadian Journal of Gerontology.

Robertson, Duncan and Reisner, Debra. 1982. "Management of Dementia in the Elderly at Home: Stress and the Supporter." Canada's Mental Health, Sept., pp.#36-38.

Rodenburg, M. 1986. "Special Facilities for Patients with Alzheimer's Disease." Canadian Medical Association Journal, vol. 134(4), Feb. 15, pp.#315-316.

Rodenburg, M. 1985. "Psychiatric and Non-Psychiatric Facilities in the Care of Psychogeriatric Patients." Canadian Medical Association Journal, vol. 132.

Rosenheimer, Lilia. 1987. "Vesper Home Care Alzheimer Case Management and In-House Respite Program, Sept. 1, 1985-Aug. 30, 1986." Paper presented at American Society on Aging. 33rd Annual Meeting. Salt Lake City, UT: March 13-17, 9 p.

Rosin, A.J., et al. 1985. "Environmental Management of Senile Dementia." Social Work in Health Care, vol 11(1), Fall, pp.#33-43.

Ross, M. 1987. Silent Epidemic -- A Comprehensive Guide to Alzheimer's Disease. Hounslow Press.

Roth, Sir Martin. 1985. "Some Strategies for Tackling the Problems of Senile Dementia and Related Disorders within the Next Decade." Danish Medical Bulletin Gerontology Special Supplement Series, vol. 32(1), February, pp.#92-111.

Sanborn, Beverly. 1986. "San Diego's Alzheimer's Family Center." Pride Institute Journal of Long Term Home Health Care, vol. 5(3), Summer, pp.#13-18.

Sands, Dan. 1984. "Use of the Burden Interview in an Adult Day Care Setting." Clinical Gerontologist, vol. 3(2), Winter, pp.#37-38.

Sands, Dan. 1984. "The Harbor Area Adult Day Care Center: A Model Program." Pride Institute Journal of Long Term Home Health Care, vol. 3(4), Fall, pp.#44-50.

Sands, Dan and Suzuki, T. 1983. "Adult Day Care for Alzheimer's Patients and Their Families." Gerontologist, vol. 23(1), Feb., pp.#21-23.

Saskatchewan, Health and Community Services. 1987. "Nursing Home Pool Manual". Regina: Health and Community Services.

Scarbrough, Michael R. Alzheimer's Disease and Presenile Dementia: Subject Analysis with Reference Bibliography. Washington, DC: ABBE 150 pp.

Shephard, M. 1984. "The Case for Respite Care." Journal of the American Geriatrics Society, vol. 32(8).

Sheridan, C. 1987. Failure-Free Activities for the Alzheimer's Patient. Oakland, CA: Cottage Books.

Shibbal-Champagne, Sue, and Lipinska-Stachow, D.M. 1985-1986. "Alzheimer's Educational Support Group: Considerations for Success." Journal of Gerontological Social Work, vol. 9(2), pp.#4-48.

Simank, Margaret H., and Strickland, Kenny J. 1985-1986. "Assisting Families in Coping with Alzheimer's Disease and Other Related Dementias with the Establishment of Mutual Support Group." Journal of Gerontological Social Work, vol. 9(2), Winter, pp.#49-58.

Simonton, Linda J. and Haugland, S.M. 1986. "Assessing Caregiver Information Needs: A Brief Questionnaire." Paper presented at Gerontological Society. 39th Annual Scientific Meeting. Chicago, Nov. 19-23, 13 pp.

Simonton, Linda J. 1987. "Assessing Caregiver Information Needs: A Brief Questionnaire." Journal of Gerontological Social Work, vol. 10(1-2), Jan., pp.#177-180.

Singer Edelson, Jacqueline, and Lyons, Walter H. 1985. Institutional Care of the Mentally Impaired Elderly. Agincourt, Ontario: Macmillan of Canada.

Southall, Wilma M. (n.d.) "What Is Special Care in a Home for the Aged?" Dundas, Ontario: St. Joseph's Villa.

Spence, Donald L., and Miller, Dulcy B. 1985-1986. "Family Respite for the Elderly Alzheimer's Patient." Journal of Gerontological Social Work, vol. 9(2), Winter, pp.#101-112.

Steuer, J.L. and Clark, E.D. 1982. "Family Support Groups Within a Research Project on Dementia." Clinical Gerontologist, vol. 1(1), Fall, pp.#87-95.

Stone, L.O. 1986. "On the Demography of Dementia." Population Studies Division, Statistics Canada and Centre on Aging, University of Manitoba. A paper prepared for the Clark Institute's 1986 Conference on Alzheimer's Disease.

Terry, Robert D. 1985. "Some Unanswered Questions About the Mechanisms and Aetiology of Alzheimer's Disease." Danish Medical Bulletin Gerontology Special Supplement Series, vol. 32(1), February, pp.#22-24.

Wasow, Mona. 1986. "Support Groups for Family Caregivers of Patients with Alzheimer's Disease." Social Work, vol. 31(2), March-April, pp.#93-97.

Williams-Schroeder, Mary L. 1985. "Meeting the Needs of the Alzheimer's Caregiver." Physical and Occupational Therapy in Geriatrics, vol. 3(4), Summer, pp.#33-38.

Winogrond, Iris R., et al. 1987. "The Relationship of Caregiver Burden and Morale to Alzheimer's Disease Patient Function in a Therapeutic Setting." Gerontologist, vol. 27(3), June. pp.#336-339.

Working Group on Legal Issues, Committee on Guidelines for Comprehensive Services to Elderly Persons with Psychiatric Disorders. 1987. Canada's Mental Health, vol. 35(2), June, pp.#6-11.

Wolk, James, et al. 1987. "Alzheimer's Disease in Rural Areas: Can Informal Helpers Meet the Needs?" Human Services in the Rural Environment, vol. 10(3), Winter, pp.#8-13

Zarit, S.H. 1983. "Families, Informal Supports and Alzheimer's Disease." Position paper submitted to the National Council on Aging, Sept.

Zarit, Steven and Anthony, Cheri. 1986. "Interventions with Dementia Patients and Their Families," in Gilhooly, Zarit and Birren, editors.

Zarit, Steven H., Orr, Nancy K., and Zarit, Judy M. 1985. The Hidden Victims of Alzheimer's Disease: Families Under Stress. New York: NYU Press, 224 pp.

Zogola, Jitka M. 1987. Doing Things: A Guide to Programming Activities for Persons with Alzheimer's Disease and Related Disorders. Baltimore: Johns Hopkins Univ. Press, 160 pp.